

# **Ill-timed Patients:**

## **Gitanos, Cultural Difference and Primary Health Care in a Time of Crisis**



Beatriz Aragón Martín

UCL Anthropology Department

A thesis submitted for the degree of Doctor of Philosophy





## **Declaration of authorship**

I, Beatriz Aragón Martín, confirm that the work presented in this thesis is my own.

Where information has been derived from other sources, I confirm that this has been indicated in the thesis.



## **Abstract**

In this dissertation I explore the multiple meanings that cultural difference acquires in everyday practices in public primary healthcare centres in Madrid. I specifically look at how Gitano' and Roma' cultural difference is understood by healthcare workers in various settings at primary healthcare. Gitanos have been living for centuries in Spain and they have been historically persecuted and segregated from wider Spanish society. Current European policies aiming for "Roma inclusion" include health as one of the strategic areas of intervention. Roma and Gitanos' health inequalities are frequently mentioned but little is known about the actual health-status of Gitanos and Roma or the difficulties they encounter when accessing healthcare facilities. Furthermore, the public healthcare system in Madrid has gone through several changes in recent years, some of them publicly contested (like various privatisation attempts, for example) others inadvertently assumed (like the budgetary cuts). Primary healthcare is the access door to the public healthcare system, but it is also a social space where broader social representations about Gitanos intertwine with different expert knowledge systems (such as biomedical or managerial knowledge) in the provision of healthcare. Drawing on twelve months fieldwork in primary healthcare centres, in this dissertation I explore how notions of cultural difference are enacted within the specific social space of primary healthcare centres, which are complex technical, moral and political sites. This dissertation engages with the debates about the complex relation of culture and biomedicine and with the anthropological literature on care to investigate the multiple uses and meanings that healthcare workers give to "cultural difference" and how and when they operationalise Gitano difference in their practices. Through the analysis of these encounters in clinical settings this dissertation sheds light on the ways that social representations of Gitanos are articulated within the institutional configurations that frame the provision of care.



## Acknowledgments



I have been thinking about the moment of writing this part of the dissertation for so long and finally the moment arrived. Actually, it has been as long as my hair in the second drawing: in the beginning of this project I considered the idea of finding a way to measure the passing of time during the PhD and I did not find any better than not cutting my hair (just the tips from time to time) and see how long it got. And four years and a half is too long, but I have been lucky enough to have great people accompanying me during this stage. People from different backgrounds and in different countries that I met during this challenging (but fascinating) trip. The drawing on the left was done during the first Christmas break of my PhD, I was in Madrid and heard that Ivan was looking for healthcare workers to draw in his portrait diary and document the healthcare workers' movement against the privatisation of public healthcare. I explained to him that I was not directly involved, but that I would love to collaborate for his portrait diary and write a little text about the contestation. Four and a half years later, I am living in Madrid again and coincidentally bumped into Ivan and thought about making a new drawing to illustrate these acknowledgments, and to show how long four years (and a half) is.

During all these years, I have been accompanied and guided by my supervisor, Sahra Gibbon, to whom I am deeply grateful for her academic generosity and kindness. She has supported this project from the beginning to the very end, giving me guidance and commenting on my work, even on the very very un-readable initial drafts. Thanks for your patience, Sahra, for your stimulating intellectual guidance and for your invaluable help during this process. I would also like to thank Michael Stewart, my second supervisor, who has also given me advice and insightful comments, and contributed to improving this dissertation. Michael was the one who introduced me to the field of Romani Studies, encouraging me to apply for the Summer University Course “Roma in Europe” at the CEU University in Budapest, where I met great interlocutors and good friends. I am really grateful for that, Michael.

The Max Planck Institute for the Study of Ethnic and Religious Diversity was my professional base during the middle part of this PhD and I am especially thankful for the generous support of the Institute director Steven Vertovec. I am also particularly indebted to Karen Schönwälder and her thoughtful comments at different stages of this research. The MPI Medical Diversities Working group also helped me structure the arguments of this thesis and I am really thankful for that (David Parkin, Michi Knecht, Gabrielle Alex and Kristine Krause). Kristine Krause has also been a source of inspiration and her encouragement and mentorship has undoubtedly influenced this research. I am very grateful to her for her inspiring advice as well as her generosity and contagious enthusiasm. In Göttingen I did not only find an intellectual home, but also a group of peers with whom I shared the everyday knitting of this research and they became a great source of encouragement. We manage not to go-crazy through our mutual support: Julia Martinez-Ariño, Michalis Moutselos, Elena Gadjanova, Maria Schiller, Damian Martínez, Lisa Björkman and Angie Heo, thanks for that.

“At home”, I have benefited from the invaluable support of my colleagues, especially from Rosa Maria Calvo Fernández, Santiago Agudo Polo, Elena Flores Preciado, Patricia Estevan Burdeus and Cecilia Alzu. This project has only been possible thanks to their generosity and I am especially indebted to them; their commitment is contagious and one of the reasons I decided to go back to medical practice. From the clinical world, I have felt accompanied by quite a lot of people that have encouraged me to write this dissertation and helped me with their comments and inspiring

conversations. I would like to thank Elena Serrano, Marta Sastre, Patricia Escartín, Javier Segura de Pozo, Juan Gervas, Mercedes Fernandez, Daniel García Blanco and all the people from the SIAP seminars. Outside of the medical world, I am greatly indebted to Blanca Gómez Bengoechea, Carmiña Lecuona, Javier Baeza, Patricia Fernandez Vincens, Francoise Bonnetier and Jorge Fernandez Crousielles with whom I have shared the ups and downs of working in the settlement and trying to do differently during all these years. Their commitment and dedication is a source of inspiration.

Over the course of these years I have enjoyed the support of those who, like me, became a little bit nomadic and found themselves on the fringes of their disciplines: Daniel Fernandez Pascual, Tyra Tingleff and Alon Schwabe were the best partners in London and elsewhere - their friendship has been one of the best things about doing this PhD. I have shared so many hours in so many libraries in different countries with Nerea Calvillo that I think now it is time we moved somewhere else. Looking forward to seeing where we get next, Nerea. Diego Villuendas has also been very supportive both in London and in Madrid, exchanging food for books and sharing the same incurable curiosity. Jorge Martín Sainz Terreros has been a great library partner during the last months and his support and help with editing this thesis has been invaluable. Raquel Buj, María Santaolaya and Cristina Navas have been my security network: together we have been through the most difficult moments this past year and, although life has lost a little bit of its brightness, having them close is a marvellous gift.

Finally, I would like to thank my parents who have always been there, nurturing me with love and making my life easier with their kindness. This thesis is dedicated to them and to my sister, Carmen Aragón Martín, always a source of encouragement. I am also thankful to my aunt Concha Pérez García and uncle José Luis Martín Díaz who have supported me since I was a teenager and pushed me to find my own way.

This research was conducted thanks to the financial support of “La Caixa” doctoral grant program (2011/2013) and the Max Planck doctoral fellowship program (2013/2015).





# Table of Contents

Declaration of authorship .....	3
Abstract .....	5
Acknowledgments .....	7
Table of Contents.....	11
Table of Figures .....	15
Introduction .....	17
1. Theoretical Background.....	24
1.1 Biomedicine, Citizenship and Humanitarianism .....	24
1.2 A Complex Relationship: Culture and Health.....	29
2. Methodology and Ethical Concerns .....	36
2.1 Methodology.....	36
2.2 Doing Anthropology “At Home” .....	39
2.3 Confidentiality Discordances I: The Clinic .....	41
2.4 Dual Role or Duplicitous Researcher? .....	45
2.5 Confidentiality Dissonances II: The Desk .....	49
2.6 Concluding Remarks .....	50
3. Thesis Structure .....	51
Chapter One: Background.....	53
1. Gitanos in Spain.....	53
1.1 Biomedical Research: Between fatalism and exclusion .....	53
1.2 Migrant Roma .....	58
1.3 Cultural Repertoires in Regard to Gitanos .....	64
2. Spanish Public Healthcare .....	74
2.1 The National Scenario .....	75
2.2 Madrid Public Healthcare: A Contested Scenario.....	77
Concluding Remarks.....	82
(Walls that talk).....	85

Chapter Two: The Admission Desk.....	89
Introduction .....	91
1. Configurations and Representations .....	93
1.1 <i>Tipos De Ciudadanos</i> (Types Of Citizens): Who Is Who? .....	93
1.2 The Hierarchy of Legitimacy.....	96
1.3 The Spaces of Citizenship.....	100
2. Practices (Encounters) .....	106
2.1 (Re)moving Legitimacy .....	106
2.2 Beyond The Protocol: Making The Acquaintance Of Gitanos.....	120
Concluding remarks .....	128
Chapter Three: The Consulting Room .....	131
Introduction .....	133
1. Configurations and Representations .....	137
1.1 Five Minutes Today, Years to Catch Up: Organizational Arrangements.....	137
1.2 “Hyperchondriac” Patients: Cultural Repertoires in Regard to Gitanos in Primary Healthcare Centres .....	142
2. Practices (Encounters) .....	150
2.1 Cultural (Re)production: Ill-timed Pregnancies.....	150
2.2 “You Are More Modern that the People of Tomorrow” .....	164
2.3 ‘They See Diseases When There Are no Such Diseases and They Don’t See Them When They Suffer From Them’ .....	172
Concluding Remarks.....	180
Chapter Four: The Healthcare Van .....	181
Introduction .....	181
1. Configurations and Representations .....	181
1.1 Participation Without Participation.....	181
1.2 The CPE Report: Recognition Through Normalization And Eradication.....	183
1.3 Tuberculosis And Its Threats.....	188
1.4 Designing The Healthcare Van .....	191
2. Interstitial Practices .....	193
2.1 “(Extra)ordinary Work” .....	196
2.2 Planned Improvisation .....	203
2.3 Playing Cards .....	216
2.4 (Trans)Positions Of Citizenship .....	220
Concluding Remarks.....	226

Conclusion.....	227
1. The map and the territory.....	230
2. Gitano and Roma difference as a matter of time.....	236
3. Gitanos and Roma difference as professional boundary.....	239
Concluding remarks .....	242
References .....	245



## Table of Figures

Figure 1. NGO flyer that sparked a polemic in the social media.....	68
Figure 2. Gynaecologist consulting room door .....	85
Figure 3. “Choose Public Healthcare” Poster.....	86
Figure 4. Paediatrician's consulting room door at the healthcare centre.....	87
Figure 5. One of the badges of the 'pro-universal healthcare' movement .....	104
Figure 6. Non-compliant patient.....	145
Figure 7. The document bag.....	218
Figure 8. Time / Legitimacy / Cultural difference diagram .....	231



## Introduction

In February 2015, El Mundo, a Spanish national newspaper, published an article in its Madrid section about the lack of heating and drinkable water in a public primary healthcare centre<sup>1</sup>. The article made reference to the difficulties the clinicians and patients faced when providing and receiving care in such material conditions, as well as the passivity of the healthcare institution to solve the problem. One of the interviewed physicians pointed to the budgetary cuts as the cause of the infrastructure deficiency and the “precarious conditions” they work in. This article was not an oddity: since the beginning of the economic crisis in 2008 and the subsequent implementation of austerity measures that have reduced the national and regional expenditure on public healthcare, articles denouncing the healthcare system’s precariousness have flourished in the media. However, in this article the following quote caught my attention:

‘The healthcare worker’s odyssey does not end here. The physician affirms that they needed to hire permanent security services at the waiting room due to the altercations occurring with patients from “Gitano ethnicity”. He confesses that sometimes they are scared of some of these patients. “They have been physically violent a few times. They reproach us... and even though it is not always because of the cold, the low temperatures make them more upset” (my translation, quotations in the original)<sup>2</sup>

---

<sup>1</sup> <http://www.elmundo.es/madrid/2015/02/01/54ccad2e268e3e4c628b458c.html>

<sup>2</sup> La odisea de los trabajadores no acaba aquí. El médico asegura que han tenido que colocar a un vigilante de seguridad de manera permanente en la sala de espera debido a los altercados que se producen con pacientes «de etnia gitana». Confiesa que muchas veces llegan a sentir miedo por el comportamiento de algunos de estos enfermos. «Han llegado a las manos en un par de ocasiones. Nos increpan... y aunque no es siempre por tema del frío, las bajas temperaturas agrandan sus enfados»

Besides the evident (and tolerated) racism in their portrayal of Gitanos as violent, the quote raises some interesting questions: what kind of institutional response is to hire permanent security instead of fixing the heating problem? To what extent is Gitanos' difference understood as the last straw that breaks an already precarious healthcare system's back? How are negative representations of Gitanos and Roma in the shared social imaginary entangled with the duties of recognition and resource distribution of public institutions such as the healthcare system? Is there a connection between scarcity and using cultural difference as a scapegoat? When this article appeared I was halfway through the analysis of my fieldwork data and it became a kind of reassurance that I was on good track, that the research and the analysis was pertinent.

In a way, this quote is an example of the kind of entanglements I investigate in this thesis: how notions of cultural difference are articulated within the specific social space of primary healthcare centres, which are complex technical, moral and political sites. In my research, I analyse the encounters that take place in public primary healthcare centres between Gitanos (and Roma) and healthcare workers and how these encounters reflect social representations of Gitanos and the institutional configurations that frame the provision of care. In doing so, I investigate the multiple uses and meanings that healthcare workers give to "cultural difference" and how and when they operationalise Gitano difference in their practices. The article is a good example of the blatant representation of Gitanos as problematic in the Spanish social imaginary and the kind of tensions that arise when Gitanos interact with public institutions. Similarly, the quote shows that when cultural difference meets austerity, negative stereotypes flourish as causal mechanisms that partially account for the deficiencies.

The illustrative interest of this newspaper article to introduce my research project is twofold: firstly, the reason why it was published in the public media comes from its capacity to create evidence about the deterioration of the public healthcare system while enduring the narrative of how austerity measures were damaging public services. In that sense, the facts described in the article fall into what Elisabeth Povinelli defines as 'events' inasmuch as it makes of the lack of heating (and the public healthcare crisis that it signals) an objective being that 'seems to necessitate ethical reflection and political and civic engagement' (Povinelli 2011, 14). During the time I conducted fieldwork (and afterwards) public healthcare went through a vexed debate



in the public sphere, as I will explain in chapter one. Secondly, it connects this ‘event’ with the identification of Gitanos in public healthcare, representing them as problematic people who aggravate the difficulties in an already deficient public healthcare.

Still, my research takes a different path: instead of focusing on the analysis of ‘events’ as such, I look at the ordinary practices at various healthcare centres, those practices that happen without being taken into account but that retain the potentiality to become events, what Povinelli (2011) calls ‘quasi-events’. Instead of focusing on critical moments such as the example of the heating breakdown, I look at the ordinary practices where the effects of the budgetary cuts rest unnoticed in the public sphere while structuring and restricting the way healthcare is provided. It is in the everyday that healthcare workers resort to and make sense of “cultural difference”, at the times when they have to make decisions about how and when to provide care and of what kind. To do so, I adopt the healthcare workers’ side to study their practices vis-à-vis Gitano and their entanglements with the different institutional and professional logics available, whilst ‘culture underlies our understanding and interactions, but its components fluctuate and are engaged differently according to issues at hand’ (Fortin 2008, 174).

The ethnographic flesh of this dissertation comes mostly from the twelve months of observed participation in and participant observation of the ordinary practices that took place in primary healthcare facilities in Madrid. These facilities include two regular healthcare centres that attend to Gitano and Roma population from different socioeconomic backgrounds and one healthcare van that provides care at an informal settlement in the outskirts of the city. Furthermore the healthcare van’s inception is a good example of the forces and alliances that transformed a quasi-event into an event, as I will show in chapter four. The choice of facilities was not casual; neither was researching Gitanos and Roma difference. These choices are related to each other and emerge from my longstanding engagement as a primary healthcare physician in Madrid. They emerged specifically from the ten-year-long job relationship with the healthcare van that is the object of inquiry in chapter four. As a physician, I had been working at the healthcare van for five years, and I interrupted my clinical practice to study anthropology with the purpose of better understanding the social processes in public healthcare facilities, especially those processes that involved the disenfranchised

population who lived at the settlement and who were my patients at the healthcare van. Eventually, I came back to practise medicine during some periods of my fieldwork and the writing up. My engagement with the field site conveyed different positionalities and roles during my fieldwork that I will address in the methodology section of this chapter.

There are three main reasons why I chose to research Gitano and Roma cultural differences: first, Gitanos embody cultural difference in the wider Spanish social imaginary (Calvo Buezas 1990; Gay y Blasco 1999; Román 1997), they are perceived as the ‘the other’ among us and they have been the object of multiple state interventions, ranging from persecution and assimilation measures, to integration policies based on segregation, as I will discuss in chapter one. Historically constructed, the otherness that Gitanos represent became the landmark to which healthcare workers have compared the new “cultural difference” of those migrants that arrived in the last decades (Seoane and Portero 2006). Arjun Appadurai refers to ‘new diversities laying upon old social organizational systems’ (2013): to some extent, in the Spanish context, it is the historical construction of Gitanos’ difference that underlies the social organisation of difference when the new migrants arrived to Spain.

Secondly, since the last decade of last century, the arrival and settlement of migrant Roma from Eastern European countries has subtly changed the Spanish Gitano landscape. Despite migrant Roma being less numerous than other migrant populations, they are highly visible in public sphere and they are usually portrayed with negative stereotypes (López Catalán and Aharchi 2012). In Spain, Roma are called Gitanos and assimilated to Spanish Gitanos with some nuances that I will show throughout the thesis. The inclusion of migrant Roma in this research (although they are less represented than Gitanos because they are quantitatively less) allows me to investigate the legal framework of inclusion and exclusion to access healthcare. Migrant Roma do not only have to cope with their negative representation in the wider social imaginary, but also with legal and immigration status issues that may restrict their rights or entitlements. This way, including Roma in the research allows for looking beyond ethnicity and investigating other variables that similarly determine difference, what Steven Vertovec (2007) coined as ‘superdiversity’.

Finally, to understand how Gitano and Roma difference is constructed and operationalised in public primary healthcare gives me the opportunity to investigate the entanglements of the inclusion logics that shape the integration programs aimed at Gitanos with the humanitarian frameworks put in place to tackle specific Gitano and Roma health problems.

As migrant Roma are called Gitanos (*gitanos Rumanos*) in my research context, and for the purpose of clarity in writing and avoiding excessive repetition, from now on when I refer to Gitanos, I include both Gitanos and Roma, and I will refer to Roma when I want to address something specific to migrant Roma in the same way that I will note if something only relates to Gitanos. I am aware of the risk of excessive homogenisation of Gitanos and Roma that this choice entails, as well as the risk of essentialisation of Gitano culture. However, as I am analysing the healthcare workers' practices and representations and not the Gitano and Roma practices and experiences, I opted to use the word that healthcare workers use to refer to both Gitanos and Roma (*Gitanos*) because it is actually the object of study, not because I take Gitanos and Roma as an homogeneous and well-defined ethnic group. In this sense, what I aim to investigate is "Gitano difference" as a category of practice that is enacted in multiple ways in the everyday practices at the primary healthcare centres. As I will illustrate throughout the thesis, the category of practice "Gitano difference" draws on various sets of ideas, such as the representations of Gitanos in the social imaginary, notions of cultural difference used in biomedical textbooks and training programs, ideas of citizenship and so on. In that sense, in the healthcare centres where I did fieldwork, both Gitanos and migrant Roma fall into the category of practice "Gitano difference", a category which is, ultimately, the focus of this research.

Public primary healthcare facilities are good sites to investigate the interactions between citizens and the state, as 'everyday encounters with the state bureaucracies are central to the routine construction of the state' (Auyero 2012, 5). Primary healthcare is the entrance door to the public healthcare system and therefore they have the key to access a fundamental aspect of citizenship, which is access to healthcare. Primary healthcare has a gatekeeper role in accessing healthcare, which in Spain is considered a (contested) citizen right. Primary healthcare facilities accommodate multiple –some of them opposing – logics: biomedical, managerial,

economical, care, and different alignments are made between these logics depending on the situated practices. Therefore, despite the neutral, aseptic and scientific icing, healthcare centres are social and political spaces that reflect the wider social imaginary (van der Geest and Finkler 2004). Sylvie Fortin describes the clinic ‘as a social space in which a set of social, cultural, structural and asymmetrical relations are played out and alliances negotiated’ (Fortin 2008, 176). Similarly, I understand primary healthcare centres as a social and therefore moral and political arena, with a specific temporality marked by the entanglement of organisational logics with biomedical temporal frameworks and where different and sometime contesting ideas about social justice, institutional purpose and good professional practices converge. Furthermore, due to its privileged position within the neighbourhoods they attend to and their gatekeeper role in healthcare access, primary healthcare clinics are a vantage point to investigate how healthcare access and entitlements are enacted and the multiple ways the idea of “Gitano difference” may influence access, if this is the case.

As other “impure” biomedical spaces – such as the archetypical hospital – the primary healthcare centre is more than a biomedical, technological or professional space, it is a relational space where multiple and competing logics coexist with personal and collective experiences and aspirations. The tensions that arise from the ambivalent role of primary healthcare as a ‘normalizing institution’ (Foucault 2009) or its role as granting access to good care was implicit throughout my fieldwork; this ambivalence was present in the multiple ways healthcare workers justified the decisions they made in their ordinary practice. Similarly, different notions about what entails being a citizen and the obligations conveyed by the right to healthcare were used to justify some practices, whereas in other instances the difficulties to distribute scarce resources abiding different ideas of justice were highlighted. I focus on those processes when healthcare workers resort to Gitanos’ identification as different to make sense of the encounter in which cultural difference comes into play. In its ordinary character, these encounters shed light on the multiple ways “Gitano difference” is problematised and when and how it reproduces unequal treatment if so. As Michael Lambek wrote: ‘Ethnographers commonly find that the people they encounter are trying to do what they consider right or good, are being evaluated according to criteria of what is right and good, or are in some debate about what constitutes the human good’ (Lambek 2010, 1). In my research I aim to unravel the different moral and professional

frameworks that intermingle and help construct an idea of what good practice with Gitanos comes to be in this context.

The thesis is structured in three main ethnographic chapters, each of which is based on a different site of primary healthcare: the ethnography is multi-sited in order to investigate the multiple enactments (Mol 2002) in which “Gitano difference” comes to light and the different aspects it reveals. Although the different sites share similar institutional and organisational logics, and the wider Spanish “social imaginary” regarding Gitanos, my assumption is that each site nurtures different relationships with the available logics (be it managerial, biomedical, care, social justice), accommodating these logics differently at particular times and in different encounters. Before the ethnographic chapters, I provide some background information about the public healthcare system in Spain and Gitano and Roma historical backgrounds in chapter one. Chapter two mainly focuses on the practices at the admissions desk while chapter three is based on the analysis of the practices in the consulting rooms. Finally, in chapter four I analyse the creation of a special healthcare van to provide care in an informal settlement, and the healthcare practices that take place there. Along this itinerary through primary healthcare, I found peculiarities and similarities in the way “Gitano difference” is identified and enacted at the admissions desk, in the consulting room or at the healthcare van. This itinerary gives us an idea not only of the logics that are available and that organise public healthcare but also their articulation with the wider social imaginary to reproduce or contest these categories of practice (Brubaker 2004) concerning Gitanos.

There are different bodies of literature that shape the theoretical and methodological approach of this research, and which I aim to contribute to by developing some of their conceptual grounds. The anthropological debates about the different ways biomedicine and medical knowledge are involved in issues of citizenship, the contested relationship between culture and biomedical knowledge and the multiple ways it has been addressed and finally, the literature on care. These different debates have informed both my research question and the analysis of the fieldwork experience.

# 1. Theoretical Background

## 1.1 Biomedicine, Citizenship and Humanitarianism

Citizenship mainly revolves about ideas of belonging to a polity and the individual rights and collective duties that this belonging entails (Cooper 2014). Rogers Brubaker highlights the salient social and cultural value of citizenship, as well as its exclusionary power: ‘As a powerful instrument of social closure, citizenship occupies a central place in the administrative structure and political culture of the modern nation-state and state system’ (Brubaker 1992, 24). Citizenship is thus, a matter of belonging and it is the state through its administrative procedures that deploys the framework of inclusion and exclusion, differentiating between citizens and aliens. In a different direction – paying attention to the shifting global landscape shaped by flows of markets, people and technologies – Aihwa Ong signals the detachment of citizenship from the previous territorial and state demarcation to become rearticulated in ‘global assemblages’ that determine zones of entitlements and claims (Ong 2006). Ong contends that ‘multiple assemblages of disparate elements create novel political spaces in which questions of living are problematized and resolved today. In zones of hyper-capitalism, neoliberal values articulate ideals of belonging by making talents and self-enterprise ideals of citizenship’ (Ong 2005, 698). Whether state or territorially defined, or in novel ‘global assemblages’ as Aihwa Ong claims, citizenship determines who has certain rights and entitlements and who is excluded from them. Both biomedical knowledge and biomedical institutions are involved in articulations of citizenship in different ways.

Firstly, drawing on Michel Foucault’s theorisation of biopower and techniques of normalisation, some scholars have studied how biomedical knowledge is involved in the articulation of different projects of citizenship, and its power to engender different kinds of subjectivities. On their hand, Nikolas Rose and Carlos Novas, in their seminal paper *Biological Citizenship*, use that same term to refer to projects of citizenship that connect their conceptions of citizenship with beliefs about the biological (Rose and Novas 2008). In the same paper, the authors admit that the biological link to citizenship is not anew: ‘Specific biological presuppositions, explicitly or implicitly, have underlain many citizenship projects, shaped conceptions of what it means to be a citizen, and underpinned distinctions between actual, potential,

troublesome, and impossible citizens' (2008, 440). Still, they conceptualise 'biological citizenship' making an emphasis on the entanglements of biological values and judgements with 'a more general contemporary "regime of the self" as a prudent yet enterprising individual, actively shaping his or her life course through acts of choice' (2008, 441). Other authors have coined the term "genetic citizenship" (Heath, Rapp, and Taussig 2008) to draw attention to the blurring boundaries between technoscience and the rest of society, stressing the new ethics of care that this reconfiguration opens up. From a similar perspective, by developing on Rabinow's concept of 'biosocialities' (Rabinow 1996) some authors have investigated the influence that different forms of patient activism have, mostly in relation with specific pathologies or conditions, on the articulation of different notions of citizenship (Gibbon and Novas 2008; Gibbon 2007; Callon and Rabearisoa 2004).

A different avenue of research on the topic of biomedicine and citizenship investigates issues of access to healthcare and the enactment of different inclusion and exclusion frameworks. On the one hand, Didier Fassin analysed the shift of biopower in contemporary humanitarian regimes and replaced it with 'biolegitimacy' (2009). Fassin uses the concept of biolegitimacy to highlight the legitimacy attached to different bodies and lives under humanitarian regimes, and its connection with values and ascribed meanings. Following Fassin's argument, Miriam Tickin (2011b) explores the increasing value ascribed to biology in the recognition of rights for undocumented migrants in France and asylum seekers in the United States. Tickin argues that this emphasis on biology is consequence of the rise of humanitarian regimes that seek in the body the measure of suffering upon which rights are exceptionally granted. Both in Fassin's and Tickin's work, the body is a tool to gain access to citizenship, but ironically it is the suffering body which gives the means to be granted rights, determining a hierarchy where there are 'disabled citizen-subjects, and a continued racialized division between humanity of the elite and underclass couched in biological terms' (Tickin 2011b, 154).

Still looking at the different frameworks of inclusion and exclusion –but this time not to access legal status but to access specific treatment– Vin Kim Nguyen (2010) refers to 'therapeutic citizenship' to understand the social processes through which a group of people suffering the same condition claim access to treatment for that condition. Drawing on his extended fieldwork in West Africa, he analyses the different

techniques of confession used to triage the best candidates for therapy and the way patients fashioned themselves incorporating biomedical discourses to maximise their chances to be treated (Nguyen 2010). In this line, Adriana Petryna (2002) introduced the term ‘biological citizenship’ to refer to the use of scientific knowledge as a tool to claim healthcare and welfare access on the grounds of being physically affected by the Chernobyl disaster. In Petryna’s case, it is the suffering body that conferred rights to access citizen rights, and the ability to prove that suffering in biomedical terms. In European and American contexts, migrant health studies have researched the different frameworks of inclusion and exclusion and patterns of healthcare access, as well as the social, political and economic conditions that relate to disease (Sargent and Larchanché 2011; Ticktin 2011; Fassin 2005; Holmes 2013; Quesada, Hart, and Bourgois 2011). Some authors focusing on access to healthcare have researched the interface between the legal frameworks that determine inclusion and the local moral judgements that materialise (or not) those rights (Holmes 2013; Larchanché 2012; Willen 2012a; Ticktin 2011a; Castañeda 2009; Huschke 2014). Using the term “deservingness” these authors differentiate between entitlements –that refer to legality and formal rights– and deservingness –signifying moral worth – and investigate how both are related: ‘popular and political understanding of immigrant “deservingness” shape and reflect formal policies and legal “entitlements”’. Thus the legal entitlements afforded particular immigrants populations may influence public perceptions and representations of their collective merit’ (Sargent 2012) Health policies determine the framework of inclusion and exclusion, but the local ways of reckoning health-related deservingness (Willen 2012b) modulate the implementation of these policies.

Research on ‘health-related deservingness’ shows how the representation of different populations as illegitimate in the wider social imaginary hinders their access to healthcare, as well as highlighting the public discourse regarding migrant and other low socioeconomic status populations sometimes as a drain for national resources or as not fitting into the national ‘body politic’ (Chavez 1986). In this line, some authors have investigated the connection between medicalisation and racialisation. For instance, Charles Briggs and Clara Mantini-Briggs’ research during a cholera epidemic in Venezuela shed light on the mechanisms put in place that racially profiled different communities at risk of cholera (Briggs and Mantini-Briggs 2003). Briggs and Mantini-Briggs describe two diametrically opposed types of citizens, which



they call sanitary and unsanitary citizens. Here they describe some of the characteristics of unsanitary citizens:

‘Unsanitary subjects lacked the broader set of characteristics that would have enabled them to adequately fit the model of the modern citizen, and thus they could be denied access to jobs, legal protections, and human dignity. [...] Because the bodies and minds of unsanitary subjects seemed to be inseparable from their despicable environments, the state had to protect them from their own natures and desires –in short, from themselves. At the same time, the state isolated its unsanitary subjects because its sanitary citizens had to be protected’ (2003, 33).

On the one hand, unsanitary citizens are defined in opposition to those ‘individuals deemed to possess modern medical understandings of the body, health, and illness, practice hygiene, and depend on doctors and nurses when they are sick’ (Briggs 2005), or what they call sanitary citizens. These categorisations of citizenship in biomedical terms reflect the hierarchies and unequal social relations of domination and oppression of the indigenous people in Venezuela. It is not about belonging to the national state, but about differentiating subaltern groups on the basis of biomedical discourses. As Aihwa Ong puts it, ‘medical regimes thus not only socialize people to expected norms of patient behaviour, but also instruct patients about the rules and rights that constitute their proper medical and juridical subject’ (Ong 1995). Inasmuch as a person has incorporated a modern biomedical relationship to her body, she is valued as a full citizen. Embracing the biomedical model of health and disease – a model based on scientific knowledge and with therapeutic claims– represents the “rational” understanding of the body in societies that praise health and well-being. The state is no longer expected to solve societies’ health needs but instead it becomes a facilitator while every citizen becomes an active partner in the monitoring and maintaining of her own health (Rose 2001). The shift from state to individual responsibilities raises one of the core questions of the politics of healthcare: whether healthcare should be conceived as a human right or rather as a commodity, and whether it pertains to matters of social justice or market forces (Rylko-Bauer and Farmer 2002; Navarro 1986; Nguyen and Peschard 2003).

On the other hand, unsanitary citizens are defined simultaneously as people who do not fit in the nation-state project from within, while eliciting the responsibility of the state to intervene on them, both to protect them from themselves and the sanitary

citizens of the risk that unsanitary citizens pose. Therefore, different public health measures and initiatives are devised to aid “unsanitary citizens” and control the risk they pose, be it creating specific tuberculosis programmes (Farmer 1997; Kehr 2012) or mental health and rehabilitation programmes (Fassin 2005b; Giordano 2014). This kind of measures are part and parcel of what Didier Fassin (2011c) describes as ‘humanitarian government’, as these measures are grounded on an ambivalent relation of domination and assistance, and justified by the moral sentiment of compassion. Fassin refers to ‘humanitarian government’ to bring our attention to the deployment of moral sentiment in contemporary politics that ultimately justify discourses and practices that promote compassion rather than justice (2011c, 3). For Fassin, humanitarian government is a politics of precarious lives: ‘lives that are not guaranteed but bestowed in answer to prayer, or in other words are defined not in the absolute condition, but in relation to those who have power over them’ (2011c, 4). There are several pieces of research that have focused on humanitarianism: for instance Mariella Pandolfi’s research (Fassin and Pandolfi 2010) on military-humanitarian interventions in Kosovo critically examines the “mobile sovereignties” created by the different organisations in conflict zones and that replace the state authorities. Miriam Ticktin, in her research with *sans papiers* in France, contends that the effects of the enactment of humanitarianism on the ground brings counterintuitive consequences such as the perpetuation of exclusion (Ticktin 2006). Peter Redfield’s analysis of *Médecins sans Frontières*’ mission in Uganda highlights the NGO workers’ feelings of moral ambivalence (shared by the anthropologist) and the constraints they have to work with (Redfield 2005). Lisa Stevenson, in her ethnography of the Canadian arctic, shows how humanitarian organisations define the provision of care in their own terms, which may potentially undermine the local meanings that makes life worth living (Stevenson 2012).

So far I have exposed the power of biomedicine to engender subjectivities, as Foucault initially exposed in his book *Birth of the Clinic* (Foucault 2003b), as well as the technologies of normalisation embedded in biomedical knowledge: the clinic as a disciplinary institution involved in the regulation of citizens as autonomous, self-regulating individuals. I have also exposed how biomedicine is no longer confined to healthcare institutions (Preciado 2013), as health becomes an ethical imperative that regulates people’s behaviour and enables different understandings of citizenship. Furthermore, the boundaries between expert/lay knowledge are blurred, making

possible new relationships between civic society, patients and biomedical knowledge that articulate citizenship. On the other hand, access to healthcare and the multiple connotations that it has both to ideas of citizenship and to the politics of healthcare has been a widely researched topic, as I have exposed. From analyses of the different frameworks of inclusion and exclusion to the investigation of the practices in which those frameworks come to light, these pieces of research have shown how access to healthcare is fraught with moral dilemmas which mainly revolve about the appropriateness of conceptualising healthcare as a human right, as a right for certain people, or as a commodity ready to be consumed. In what follows, I move forward from these debates regarding access to the debates about medical practice itself and those debates concerning the provision of healthcare. I will begin by examining the literature on medicine and culture (and the culture of biomedicine) to subsequently examine literature on care.

## **1.2 A Complex Relationship: Culture and Health**

In November 2014, the prestigious medical journal “The Lancet” dedicated its special commission to the topic of “Culture and Health” (Napier et al. 2014). An interdisciplinary team from different fields of the social sciences and medicine produced an extensive report analysing the most up-to-date relationship between culture and health. Published in a medical journal with worldwide distribution, the report was addressed to readers from a biomedical background to expose the interrelation of culture and health, analyse how culture has been problematised in biomedical knowledge and to propose new strategies to reverse ‘the systematic neglect of culture in health, the single biggest barrier to advancement of the highest attainable standard of health worldwide’ (Napier et al. 2014, 1608). Leaving aside the somewhat ostentatious tone of the quote (not infrequent in biomedical journals), it signals how the way biomedicine and its institutions treat culture is problematic and a source of inequalities in itself.

Culture has received increasing attention in clinical context in the last decades from different perspectives and latitudes: maybe the most salient example for its institutionalisation and subsequent adaptation in other regions is the US model of cultural competence. Cultural competence emerged as a framework for addressing diversity and inequality in the US in the 1980s. Advocates of cultural competence

claimed that it was the way to address the bias and prejudice of the biomedical gaze, which focused only on biological signs but did not pay attention to symptoms (those non-biological, either cultural or moral realms which are not what biomedicine cares about). The introduction of culture in the diagnosis process would liberate the clinical encounter from the homogenising medical gaze and would adapt care to the patient's specificities (Kleinman 1978). From then on, alternative concepts to cultural competence have blossomed, for instance 'cultural humility', 'cultural responsiveness', and so on (see a review of the evolution of cultural competence in (Kirmayer 2012)). This range of expressions reflects the uncertainty over what is culture and its relation to medical care and what should be the purpose of increasing attention to culture in healthcare (Jenks 2011). Still, despite the institutionalisation of cultural competence learning programs aimed at promoting adequate care to minorities, the Institute of Medicine issued a report called *Unequal Treatment* that showed that inequalities and disparities in treatment persisted (Institute of Medicine 2003).

The cultural competence model has been criticised from different perspectives: the most controversial point is its essentialised and fixed approach to the notion of culture while this notion is conflated with racial and ethnic categories that seem to exist primarily among the exotic 'others' (Jenks 2011; Shaw 2005; Taylor 2003). Other authors have underlined how the focus on culture diverts attention from structural inequalities (Fassin 2011a; Gregg and Saha 2006; Ong 1995; Santiago-Irizarry 1996). Actually, medicine mainly revolves around differentiating between the normal and the pathological, the latter being usually associated with a deviation from statistical average (Hacking 1990; Canguilhem 1989). Therefore, deviations from a "normal" culture tend to be taken as another factor that either impedes effective treatment or as pathologies themselves. For these reasons, Lambek and Sevak (1996) question the usefulness of 'cultural difference' as a concept to aptly investigate differentials in health status. They contend that both the narrow and simplistic characterisation of culture used in ethnic health research and the self-evident assumption that cultural differences are connected with ethnic affiliation mean that most of the research has limited value in explaining differences in health status. This kind of approach is affected by the 'ethnic bias', an expression used to refer to the overdetermining power of ethnicity when it is the research focus, described by scholars in ethnic and racial studies (Fox and Jones 2013).

Despite the controversies and cautions that cultural competence (et al.) programmes pose, its blossoming during the last decades points to the need of clinical facilities to adapt to the diverse populations they attend to and to the demographic changes caused by new waves of migration from new countries (Meissner and Vertovec 2015). Healthcare institutions react slowly to accommodate the needs of a rapidly changing population (Phillimore 2015). However it is important to bear in mind the context where these demographic changes are taking place and how, for example, in Europe, a number of authors have warned of the rise of xenophobic discourses questioning migrants' basic rights (Grillo 2007; Stolcke 1995; Vertovec and Wessendorf 2010). What Verena Stolcke (1995) calls 'contemporary cultural fundamentalism' to refer to the logics behind these xenophobic discourses. Stolcke argues that 'contemporary cultural fundamentalism is based, then, on two conflated assumptions: that different cultures are incommensurable and that, because humans are inherently ethnocentric, relations between cultures are by "nature" hostile' (1995, 6). Culture difference is thus, a contested issue in public sphere that triggers different understandings about the role of the state and its institutions, public healthcare among them.

In this line and going beyond the critique of the different models of cultural competence, Cristiana Giordano has researched the uses of 'culture' in an ethno-psychiatric clinic in the North of Italy that mainly attend to asylum seekers and victims of human trafficking (Giordano 2014). Giordano shows how reified notions of culture become a tool to create shared meanings with the patients in that clinical setting and to obtain the needed residence permit. Giordano highlights the complexities and ambivalences imbued in the process to be granted citizenship and how a reified notion of culture has the potential to render a person recognisable for the state. Giordano contends that

'to apply anthropological theory to the clinical use of culture is misleading and risks missing the point of the political valence of the use of culture in this specific context. The kind of reification I am referring to here is only a temporary tool of recognition, an attempt to translate difference in terms that are intelligible to patients and doctors' (2014, 67).

Giordano is drawing our attention to the need to investigate the situated practices and the multiple ways that cultural difference is made sense of and used for. In that sense, her ethnography is an excellent example of the counterintuitive consequences of using

cultural difference in clinical settings to disagree with the policing mechanisms of the state ‘which claims to know foreign others through categories such as victim, migrant and political refugee’ (2014, 9).

Giordano’s research also points to an important aspect of clinical practice: multiplicity. As several authors have argued, biomedicine is not a monolithic unity but an heterogeneous coalition of practices (Berg and Mol 1998; Good 1995; Lindenbaum and Lock 1993). Instead of approaching biomedicine as limited to the physical (following Foucault’s argument of the clinical gaze) in need of a social and cultural supplement to better attend to their patient physical needs (perhaps the approach of most cultural competence models), some authors adopted a different perspective and investigated the multiple ways in which clinical practices and technologies shape people’s bodies and lives, taking patient’s views as a matter relevant to debates inside biomedicine, not as something to put next to or on top (Berg and Mol 1998). This kind of research puts practices on the foreground and it is in these practices that truths and norms are mobilised, by some people and not others, in specific situations (Mol 2002). Annemarie Mol argues that ‘knowledge is no longer treated primarily as referential, as a set of statements about reality, but as a practice that interferes with other practices’ (Mol 2002, 153).

These approaches to the study of biomedical practices have informed my research both theoretically and methodologically. Following Mol (2002), I focus on the socio-material-semiotic practices encompassing people as well as technologies, resources and infrastructures to investigate how cultural difference is enacted within these practices. Thus, methodologically I focus on the situated practices as they reflect broader social representations and configurations. I engage with the literature on care (Pols 2006; Pols and Moser 2009; Mol 2008) that investigate the enactments of care in different contexts, some of them clinical settings. These approaches that consider the ways care is enacted while tracking the paths by which it circulates, ‘enable analysis that neither romanticizes care as separate from political economy nor reduces care to power altogether’ (Buch 2015) In that sense, Annemarie Mol’s book ‘The Logic of Care: Health and The Problem of Patient’s Choice’ (2008) is exemplary. In ‘The Logic of Care’ Mol aims to articulate which are the elements that inform good care while comparing it with the logic of choice, which would correlate with the logical underpinning of Rose and Novas’ ‘biological citizen’ (2008): an informed, active

patient that makes informed choices. Through ethnographic research in a Dutch diabetes clinic, Mol unravels the differences between both logics and sketches what good care is about. While choice is built up in a logic of standardised medical practices encompassing the latest “research evidences” (Timmermans and Berg 2003) efficiently managed by the organisation and presented as a commodity ready to be consumed (Rylko-Bauer and Farmer 2002), Mol describes care as a matter of doctoring: ‘doctoring depends on being knowledgeable, accurate and skilful. But added to that, it also involves being attentive, inventive, persisting and forgiving’ (Mol 2008). Mol’s use of the word doctoring despite of its negative connotations reflects her aim to contribute to improving healthcare ‘on its own terms, in its own language. A language in which the main emphasis is not on autonomy and the right to decide for oneself, but on daily life practices and attempts to make these more liveable through inventive doctoring’ (Mol 2008, 97).

These two logics of care and choice, along with others such as organisational logics based on economic effectiveness, coexist in clinical settings and are articulated in practice in relation to different ideas of the good. Drawing from Joan Tronto’s theory on the ethics of care (Tronto 1994), Mol, Moser and Pols argue that ‘in care practice it is taken as inevitable that different “goods”, reflecting not only on different values but also involving different ways of ordering reality, have to be dealt together’ (Mol, Moser, and Pols 2010, 13). The focus on practices underlies the analysis of these negotiations between different “goods” in specific, local practices. White et al. contend that as the different logics that coexist in hospitals are incompatible they are negotiated, timing them, making some logics present or absent at different moments and in different practices (White, Hillman, and Latimer 2012). Jeannete Pols (2006) talks about ‘repertoires of practices’ to refer to the different modes of ordering triggered by the negotiations between the existing logics.

Drawing from these bodies of literature, my research aims to investigate “Gitano difference” as it is operationalised in the practices in which it comes into being. The practices that I investigate are those that could be broadly framed as ‘primary healthcare’ and which I divided in three different spaces: the admissions desk, the consulting room, and a “consulting room” outside the healthcare centre (the healthcare van). Each ethnographic chapter is dedicated to the analysis of the

different negotiations between the coexisting logics in situated practices with Gitano patients.

In this research, Gitano culture is not an analytical category (i.e. investigating what pertains to Gitano culture and what does not) neither is Gitano culture taken for granted as a preexisting and reified notion to be analysed. Instead, the research aims to unveil how Gitano difference becomes a category of practice for those healthcare workers I conducted research with and to what extent this category is built upon ideas of cultural difference and ethnicity as presented in biomedical literature.

Drawing on the previously exposed anthropological debates that question cultural difference as used in biomedical research and practice, the research investigates how “Gitano cultural difference” is constructed in the clinical encounters at the healthcare centres where I conducted research. By doing this, I investigate the process and practices by which cultural difference, specifically Gitano cultural difference comes to light and the different meanings that it is given and that it sustains, as well as how it relates to issues of citizenship in every different context.

Throughout the thesis, the notion of “Gitano culture” is questioned and analysed in the context that it appeared, both in clinical practice and in the biomedical research about Gitanos, drawing connections between both. In the latter, “culture” is mainly used as an oversimplified concept conflated with racial and ethnic categories, as the following quote from a biomedical article illustrates: ‘The nomadic lives and cultural peculiarities of Gypsies made them an ethnic group that seldom integrated with other societies, endogamy being almost complete in the gypsy community.’ (de Pablo et al. 1992:187). In most of these articles, culture is reduced to another quantifiable variable that has an impact on the health status of Gitanos and Roma.

At the healthcare centres, healthcare workers used the word “culture” (*cultura*) less frequently to refer to “gitanos distinctiveness”, but still *cultura* becomes explanatory to understand certain behaviours or patient decisions, as this quote from an interview illustrates: ‘I have a lot of HIV patients that abandon or refuse treatment because of the stigmatization that the disease has in their culture’ (GP). In chapter three I further analyse how healthcare workers use *cultura* in the case of teenage pregnancy and its explanatory power to make sense of what is perceived as a social disgression. Nevertheless, in clinical practices Gitano culture is most frequently evoked through



other idioms, such as making allusions to Gitanos' way of being, Gitano's style of life and so on: 'what I have realised is that they (Gitanos) need something more anarchic, I believe that Gitano population is not used to' (administrative clerk). The frequent allusion to the idea that Gitanos are a closed community who isolate themselves from the rest of the population is also in relation to this idea of Gitano culture as 'a substantiated reality, in other words with an existence of its own, separated from the social world, homogeneous through a particular group' (Fassin 2001, 301). Statements about the Gitanos isolation and group closeness (such as shown in the quote from the biomedical article) were not infrequent in clinical facilities as this quote from an interview shows: 'they talk among themselves because, you know, they are a closed community' (administrative clerk).

Still, the use of culture in essentialised terms -as preexisting by itself outside of the social world that brings it to light- to explain those behaviours that are deemed too different was questioned in certain occasions, as this quote from an interview with a GP shows:

'well, ok, let's say that Gitanos as a collective, now that we are attending the Bangladeshi forum, I mean, that Bangladeshi people and Gitanos are collectives that are as heterogeneous as the Iberians, the people from Aragon (region) or the people from Chamberi neighbourhood [...] maybe what we define as culture does not define people more than any other variable, that maybe it (culture) does not explain the differences between people.'

So culture itself appears to be a contested category that does not have an unique meaning among healthcare workers but instead, they recur to different meanings of "cultural difference" in order to make sense of their practices. To track these multiple meanings ascribed to Gitano difference at the different places in the healthcare centres and to unravel how Gitano cultural difference is constructed as a category of practice in the various situated practices is the main purpose of this dissertation. In what follows, I provide the methodological background of the research and reflect on the ethical concerns generated in carrying out the fieldwork.

## **2. Methodology and Ethical Concerns**

I collected the ethnographic material for this thesis during twelve months of uninterrupted fieldwork in three different public primary healthcare settings in Madrid. Most of the ethnographic material I draw on in this dissertation comes from that period of time, although I exceptionally use other materials that come from my previous knowledge of the field<sup>3</sup>. During those twelve months of fieldwork, I also worked as a physician at the healthcare van for five months. This was not a personal choice but an institutional requirement both to obtain the ethics clearance to carry out research in clinical settings (a requirement I will further analyse) and in order to maintain my position as a physician at the healthcare van, which I actually chose to keep. Therefore, I would argue that there are two main characteristics that define my fieldwork: it can be defined by its multi-sitedness and an “home-based” character.

### **2.1 Methodology**

To start with, I am going to address the multi-sited character of the fieldwork: initially, during the research design I planned to investigate the Gitanos’ experiences in primary healthcare, an objective that I ultimately discarded, but that triggered an initial search for different healthcare centres that attended Gitano populations from different socioeconomic backgrounds. I visited some healthcare centres and investigated the kind of population they provide for; I selected two possible candidates and only one of them accepted to host me as a “participant observer”. I now believe their decision to allow me to observe their practices and (occasionally) make intrusive questions was influenced by the good professional relationship I have with two people who work at that healthcare centre. The choice to conduct research in two different healthcare centres (instead of just one and the healthcare van) gave me the opportunity to widen the scope of the practices I managed to observe. It also allowed me to move from the familiarity of “my healthcare centre” to a less familiar milieu (yet not completely unknown).

---

<sup>3</sup> I used those materials in chapter four as they are mainly in relation to notes from the CPE council meetings I attended where the healthcare van was designed.

My fieldwork was multi-sited not only in terms of being located in different facilities but also because within those facilities I observed different sites. At each healthcare centre I carried out participant observation at the admissions desks and in the consulting rooms of physicians and nurses. During the months I was working as a physician at the van, I would go earlier to the centre and observe the practices at the admissions desk and stayed in the afternoon to observe the practices in the consulting rooms. Some afternoons I stayed at the admissions desk too. This meant long working hours that would end with the writing daily observations in the field diary. The way I proceeded to observe the consultations was to schedule in the weeks when I would accompany a physician or a nurse during her working hours. Some of them declined to let me observe their practice or made excuses that ultimately made it impossible for me to access their practices. The most difficult group to access were the locums as they were usually hired for a few days and I did not manage to accompany them in their practices. I managed to accompany fourteen physicians on their practices out of the thirty-four who work in the healthcare centres during the time of my fieldwork. Usually, I tended to stay at least one week but sometimes I stayed a little bit longer, and other times less. With the nurses I did a more irregular participant observation. I also tried to schedule fixed periods to accompany them in their everyday practices but it did not work, in part because they organise their work differently. Usually they have one day when they are at the treatment room attending to the emergencies, another day they are in charge of home visits, and so on. So, I followed them at these sites and, for a while I stayed at the treatment room with whoever was scheduled for that day. This was a good way to approach nurses, as I was a helping hand instead of calling someone else for help, and someone with whom to talk during the (not-so-frequent) quiet moments. Out of twenty-six nurses I did participant observation with twelve. In both consulting room settings I was sitting next to the physician or nurse and usually introduced as a colleague (not an anthropologist) who was conducting research to the patients. Just a few people asked for more information and on a few occasions I had to leave the room because the patient wished so. I also left the consulting room in some situations when I felt that my presence would make the patient uncomfortable. I recall this happening just five or six times. While I was doing participant observation I realised that patients are used to the presence of someone else apart from their physician or nurse during the consultations, maybe because both

healthcare centres are training centres for physicians and nurses residents in the general practice programme.

Participant observation at the healthcare van was quite challenging. I accompanied the physician and nurse for one week and during the day, on top of the shared consultations with the nurse during the time of fieldwork I was working at the van. When I tried to observe the physician's practices, it was very difficult not to participate as a doctor as patients would approach me directly to ask about their health. As I will explain in chapter four, at the van there is no division between physician-nurse practice and they usually attend to the patients together. As a result my observing their practice actually often and easily mutated in me working with them. Ultimately, I decided to prioritise the observations of other consultations that were completely unknown to me and draw on the observed participation (Fassin 1992) I did during the five months I worked at the van.

At the admissions desk, the public character of the site facilitated participant observation; at "my healthcare centre" administrative staff were used to having people around looking for forms, asking for prescription paper, chatting behind the desk in-between shift periods. As a result my presence there became something usual as I normally used one of the admission area computers (and asked the admission desk clerks incessantly for things, as well). We had a cordial relationship and, similarly to the nurses in the treatment room, they were glad to have me around in case they had any doubts I could help solving. At the second healthcare centre, there were different reactions to my presence among the administrative staff, some people were more collaborative and others just did not paid attention to me. Furthermore, the admission desk is much smaller and it is partially closed with a protective glass, so both because I was not so familiar with the administrative staff and the size of the space itself, I felt my presence was much more evident. In total there were sixteen administrative staff.

In addition, I did another kind of observation in a different site: the hospital. On those occasions, instead of accompanying healthcare workers during their daily duties and sitting next to them, I accompanied some, mainly Romani, women to the hospital for their pregnancy follow-up appointments and was sitting on the patients' side. I started doing this kind of accompaniments at the beginning of my fieldwork, as they were a

means to investigate Romani's healthcare experiences. In this way, I also had the opportunity to contact the gynaecologist directly while accompanying the woman and ask them for an interview. However, mid fieldwork I realised that I would not manage to cover so many points of view rigorously (Gitanos, hospital workers, primary healthcare workers...) and I became aware of the difficult position I was in by attempting to talk about Gitano and Roma healthcare experiences (being the general practitioner of some of them, being a doctor myself, acknowledging the heterogeneity of experiences and the risk of the ethnicity bias (Fox and Jones 2013)). Therefore, I stopped accompanying new women to the obstetric consultation and just continued with those women I had agreed to accompany before. Yet, in chapter three, I use one ethnographic vignette from one of those accompaniments and explain why I decided to include it.

Finally, I have conducted several interviews with primary healthcare workers: I recorded thirteen semi-structured interviews with physicians, ten with nurses and five with administrative staff. Sometimes it was difficult to find the time to conduct the interviews, which were always during working hours (except the two interviews I conducted with the van workers). I also had short conversations about my research topic during coffee breaks and during walks to patients' houses. I noted these conversations usually as soon as I could after they took place, excusing my absence to leave and write down the conversation. These notes were extremely useful and gave me very good insights for the subsequent analysis. I conducted and recorded three group sessions where I provided some data about the biomedical research on Gitanos' health status and where we discussed that data and their experiences with Gitano patients.

## **2.2 Doing Anthropology “At Home”**

In multi-sited fieldwork where the researcher needs to resort to different professional roles, while mobilising personal dimensions, multiple and complex dynamics take place. This is very much the case for those conducting fieldwork in clinical settings and for medical anthropologists who work as clinicians in that same or a similar context. Ethical and professional concerns arise in this form of research, which are usually addressed in varied ways, profiting from the multiple positions the researcher could adopt. To start with, when conducting fieldwork in a familiar context the

researcher's role is outweighed by her previous role as a colleague and it is only in specific situations that her role as researcher gains prominence. This imbalance of roles favours the development of the research project as the influence of an 'external observer' during fieldwork is minimised, while the researcher has to deal with the feelings of conducting research among colleagues in a situation where, even though the researcher's role is explicitly stated, it de facto works as "covert research" (Sarradon-Eck 2009)

Secondly, after the fieldwork, during the subsequent write up process, the challenge for the physician-anthropologist is to 'cut the networks of fieldwork'(Strathern 1996). While exiting the relational web of fieldwork, the anthropologist-physician relegates her medical role and immerses herself into the reflexive work of understanding the processes through which particular events, practices and ideas come to appear meaningful to those who are studied (herself included). However, to what extent is it possible to exit the "relational web of fieldwork" when we do anthropology at home? In this case, the exit from fieldwork is hindered by a social and professional relationship with the research subjects, relationships that existed previously to fieldwork and will ideally continue after the research is completed. It is not difficult to understand that the researcher may imagine the possible ways their colleagues can react to their 'objectivation' in the ethnographic account as her career is at stake. Moreover, this social relationship with the also dual "colleagues-research subjects" may implicitly bear the researcher's ethical obligation to those who helped her with time and materials, somehow establishing the limits of what should be known, revealed or written (Mosse 2006, 944). The ethical obligation of the researcher with her "colleagues-research subjects" can be in conflict with the researcher's analysis, giving rise to feelings of disloyalty or betrayal.

This imbalance of roles (physician/anthropologist) and confidentiality (disclosure/restraint) is crucial to understand ethnographic research at home. Even though both anthropology and biomedicine have the same "study-object", both disciplines differ in the way they address it. The creation of symbolic boundaries (Michèle Lamont and Molnár 2002) between the roles of anthropologist and physician, and the balancing of both roles while conducting ethnographic research are enmeshed in a web of affects and emotions that influence the research itself. In this thesis my stance is neither that emotions affect the research project from outside

(in the case of the socio-professional relationships established before and during fieldwork) nor inside (as my own feelings about my dual position and my different positionalities while conducting research). I follow Sara Ahmed (2004) argument about the sociality of emotions. For Ahmed ‘emotions are not ‘in’ either the individual or the social, but produce the very surfaces and boundaries that allow the individual and the social to be delineated as if they are objects’ (2004, 10). This understanding of emotions not as a psychological phenomena but as social constructs enables me to unpack the complex process of delimitating the boundaries between the role as anthropologist and the role as physician and the different context where these boundaries are transgressed or reinforced. These transgressions entail ethical issues, which bring up emotions. When looking at how emotions configured the idea of ‘we’ and ‘us’ in the fieldwork, with the researcher being part of that ‘we’ with her “colleagues-research subjects”, to later abandon that ‘we’ to become an ‘I’ outside, the affective economy of the relationship is made explicit. My argument is that investigating these emotions can shed light on the ambivalent positions that the researcher needs to negotiate when researching “at home”. Therefore the negotiation of these positionalities is embedded in ethical and methodological divergences, which is what I aim to elucidate.

### **2.3 Confidentiality Discordances I: The Clinic**

Several authors have noticed that anthropological research takes place more and more in the ‘natural milieu’ of the researcher (Olivier de Sardan 2010; Mosse 2006; van der Geest and Finkler 2004). These authors highlight the advantage of using the professional experience and materials from the researcher’s professional background as research objects, in addition to the advantage of membership to grant access to closed research sites. Gaining access to the field when conducting research in hospital or healthcare facilities is fraught with uncertainties and bureaucratic difficulties<sup>4</sup>.

---

<sup>4</sup> Some salient examples of how access to the field is mediated by acquaintances, unexpected coincidences and to some extent the luck to meet the right person at the right moment are: Annemarie Mol’s account about how she got access to the Dutch diabetic clinic where her book the logic of care is based (2008) or Khiara M Bridges (2011), who explains in her book ‘Reproducing Race’ how she got access to the hospital by asking Prof Rayna Rapp for ‘sensitive’ contacts that may allow her research project at a New York Hospital.

Hospital ethnographies are not abundant: Sjaak van der Geest and Kaja Finkler (2004) claim that one element connected with the scarcity of anthropological research in hospitals may be the reluctance of healthcare workers to allow strangers to observe their practices. For her part, Marcia C. Inhorn (2004) signals to patients' right to privacy and the privatisation of healthcare services as aspects that may restrict access to hospital fieldwork. On the other hand, there are important examples of physicians-anthropologist who have conducted research in healthcare milieus, for instance Roland Littlewood (1997), Vihn-Kim Nguyen (2010), Paul Farmer (1999) or Didier Fassin (1992) among others. In my case, I gained access to the field through membership. The problem of accessing closed organisational worlds such as healthcare services can be sidestepped through membership to the professional group studied, albeit it entails some ethical concerns about the researcher's position during the research. Didier Fassin (1992) reflects on his dual role as a physician and sociologist and the double ethical mandate: on the one hand the physician's duty of providing care to the patient and, as a sociologist, understanding that the care he provides is a counter-gift. Fassin makes explicit the epistemological incompatibility between both disciplines and the power differences that were at stake during his research. Likewise, Ian Harper (2007) compares the new ethical requirements he needed to comply with to conduct research in Nepal with the previous requirements he needed to do fieldwork in the same location and he engages in the on-going debate about ethical permissions and specifically about "informed consent". An interesting remark in Harper's article is the acknowledgment he makes of how he feels about ethical requirements: 'A certain "ethical anxiety" (Faubion 2003), then, never left me as I researched, defines my subject position as an anthropological researcher and continues to haunt me today as I write and publish' (Harper 2007, 2224). Drawing on some examples of his relationship with research participants in a previous project in Nepal, he exposes the emotional background that accompanies his fieldwork and writing when considering ethical issues: the emotion he refers to is "anxiety". Reading Harper's paper I am able to identify with that "ethical anxiety" during my research and its company not only during the fieldwork but also while writing. What is the substance of that emotion and how is it related to the dual role of anthropologist-physician? I will try to unravel the bases of this anxiety first by explaining the ethical clearance process I needed to be able to perform my fieldwork.



As a first step, I asked for the research project's approval from the UCL's ethics committee, just to discover that it would be granted on the bases that the Spanish hosting institution (the regional public healthcare system) gives its ethical clearance. Then a virtual pilgrimage through several healthcare research offices and committees began, a process that took more than six months and a considerable number of e-mails. I discovered that first I needed to obtain approval from the primary healthcare research committee, an approval that was conditioned by the approval of the UCL ethics committee. When the primary healthcare research committee evaluated the project, they recommended obtaining the quality and patient care committee agreement to conduct the research. The latter asked me to make some minor changes in the interviews and after that they inquired about my contractual status with the public healthcare system: it seemed that only public healthcare workers were allowed to conduct research within the institution. Luckily enough, I was still an employee (although on student-leave) and they granted me permission. Nevertheless, the logical underpinning of the access restriction to researching in healthcare facilities to those who are not healthcare workers disturbed me. It was because I, bearing the physician role, was not "ethically problematic" in the sense that I would comply with the ethical mandates of my role as a physician, i.e.: confidentiality and non-maleficence. For that research committee, being an insider assured the observance of these ethical precepts. However, once the ethical clearance was granted, it was the researcher's responsibility to comply with an ethical code that to some extent can thwart her research as anthropologist.

The imbalance between my role as an anthropologist and as a physician began during fieldwork, when I had to continuously negotiate my position in relation to confidentiality. Confidentiality is cherished in clinical settings as a means to protect the patient and it is the base of a trustful clinical relationship. The ethnographer, by contrast, seeks to establish a trusting relationship in order to understand how their research subjects make sense of their world. The "ethical anxiety" I feel about my research has to do with how to deal with this double commitment to respect confidentiality and maintain the trustful relationships I have with my colleagues-research subjects, while profiting from these trustful relationships to produce anthropological knowledge. The classical means to guarantee confidentiality through anonymity do not seem enough in this context: someone who checks my professional profile can find the primary healthcare centre where I have been working as a GP

and thus, find out where the fieldwork was conducted. Even if I anonymise the research participants, group and professional identifications can be done. Another question is to what extent I can use the comments written in the clinical records, even when I anonymise them: If I use them in the research, am I breaking the principle of confidentiality as it is established in healthcare contexts? If I do not use clinical record comments, I am omitting an important source of information to understand the meanings and enactments of cultural difference in this context. Even if I decide not to use them, is my knowledge of those notes not somehow influencing the theoretical argument of the research? Even though there are some rational solutions, or at least theoretical justifications to use anonymous confidential information obtained in clinical practice, the “anxiety” about what is ethically correct and what is not remains.

I suggest that what it is at the heart of Ian Harper’s “ethical anxiety” (and my own) is the epistemological incompatibility that Didier Fassin (1992) refers to: how to be a doctor and how to be an ethnographer and comply with the requirements of both disciplines when they collapse in the same milieu. The need to fulfil biomedical ethical mandates and their interference with anthropological research commitments sketches the boundaries between both disciplines. The anxiety arises when the researcher has to negotiate between different disciplinary expectations, while the disciplinary boundaries are made explicit by the emotion itself. Sara Ahmed puts it this way: ‘rather, it is through emotions, or how we respond to subjects and others, that surfaces or boundaries are made: the ‘I’ and the ‘we’ are shaped by, and even take the shape of, contact with others.’ (2004, 10). Even though the broad ethical principles that shape both biomedical and anthropological research (i.e.: non-maleficence, autonomy and confidentiality) are the same, the interpretation of these principles differs from one discipline to the other, essentially in the implications of confidentiality and its relation with non-maleficence. Despite obtaining the multiple ethical committees clearances, which as I have previously stated were granted on the basis of the researcher’s dual role, the researcher has to deal with her duality in a manner that may make her feel duplicitous, a feeling that, as I will develop in the following section, is nurtured by the imbalance between these roles.

Despite the ethical anxiety and the epistemological incompatibility between medicine and anthropology, I, the dual researcher, need to make my way to continue with the research project. Paradoxically, the way I found to cope with the tensions between

biomedical ethical framework and anthropological research requirements was what Michael Lambek (2010) calls 'ordinary ethics'. Lambek describes ordinary ethics as: 'and ethic that is relatively tacit, grounded in agreement rather than rule, in practice rather than knowledge or belief, and happening without calling undue attention to itself' (2010, 2). Ordinary ethics, or making judgements to mould the rigid ethical mandates while observing the core ethical principles of biomedicine and anthropology, was a meaningful means to manage the "ethical anxiety" and a way to break the rigid boundaries between the anthropological and the biomedical roles. The moulding of the ethical framework consisted in hierarchically reorganising the biomedical ethical principles (Sarradon-Eck 2009) bearing in mind the needs of anthropological research. Through ordinary ethics the boundaries between both disciplines are transgressed and the biomedical ethical framework is reinterpreted from an anthropological perspective.

#### **2.4 Dual Role or Duplicitous Researcher?**

At "my healthcare centre", most of my colleagues supported me when I told them that I would be away for some years to study anthropology; similarly they supported me when I presented the research project at one of the staff meetings and asked for their collaboration and consent to conduct fieldwork with them. As I previously mentioned I gained access to the second healthcare centre through a good professional friend that was working in that centre. In this case I did not previously know the healthcare staff, neither did I have first-hand knowledge of the neighbourhood. The day I presented the research project to the healthcare staff, the head of department introduced me as a general practitioner and not as an anthropologist. It seems to me that the choice of presenting me as a peer has two possible explanations: firstly, that the introduction was a tactic which aimed to create more collaboration among the healthcare staff, avoiding raising suspicion. Secondly, that the physician's role is much better known in this context than the anthropologist's role and thus, it is easier to identify the researcher with the former. As Alina Mercan found in her research, informants tend to identify the researcher with the role they know better: for example, if the informant is more familiar with the medical profession than with anthropology, they ascribe that identity to the researcher (2009, 6).

It is important to clarify that for some research subjects, the medical anthropologist's role did not bring any clear idea of a professional role at all and, if one, it would be related to a fictional character in a TV series (who was in fact a forensic biological anthropologist). This lack of references to a professional role triggered a kind of uncertainty about how I was to gather the necessary data for my research and how the healthcare staff could help me to do so. The lack of familiarity with qualitative methods raised some concerns about the validity of the research and its objectivity; we must bear in mind that in this context most healthcare workers are more used to quantitative research methods. It was difficult to show them that observation did not mean that I aimed to evaluate their practice but that it was a way to understand the implicit meanings ascribed to cultural difference. At the beginning of fieldwork, I decided to translate the research project into a more accessible language for healthcare staff, as the social sciences language used was perceived as alien in one of the first presentations I gave at a staff meeting. During that first meeting, most of the research participants uttered reservations about what they perceived as the "utility" of the research and, as I previously mentioned, the research objectivity. If I wanted to engage the healthcare staff in the research, I needed to talk to them in a way they recognised as their own and from there, introduce a wider perspective. Finally I found that the best way to translate the research objectives was to use the epidemiological framework of the social determinants of health and from there, open the debate to issues of ethnicity and culture. From that starting point, we (research subjects and I) managed to create a dialogue and reflect on some aspects of clinical practice in a meaningful way for both. Still, I felt that most of these conversations were based on my role as a physician. Reflecting about the translation process I did, I acknowledge I was feeling duplicitous as I was presenting the research not in its own terms but in a more palatable version for the research subjects in order to gain their trust and collaboration. One way to cope with this duplicitous feeling was rationalising it as something necessary to make the research understandable and engaging to my colleagues. In an ideal world, I would have managed to awake my colleagues' curiosity and interest in a perspective different from biomedicine, but in the real world I did not manage to transmit the same enthusiasm I felt towards the social sciences. Thus, I fell back to a tailored version of the biomedical approach.

So far I have shown how the physician role had a predominance during fieldwork due to the familiarity the research subjects have with this role and the way I profited from

it to avoid scepticism about the research project. Interestingly, though the research subjects negotiated and acknowledged my different roles as researcher and as physician in different encounters. For example, during fieldwork at the primary healthcare centre where I worked, in everyday clinical practice, most of the healthcare staff treated me as a physician, with no differences from the kind of relationship we had before I started the research project. The weight of the previous relationship as colleagues or co-workers was bigger than my new position as a researcher, which tended to be forgotten during everyday interactions. However, my position as a researcher was privileged in those occasions when the interaction was exceptional or outside of the everyday routine of the healthcare centre: these exceptional situations were the interviews I conducted with them and when I asked them to observe their clinical practice at the consulting room.

During the interviews, there was a balance of both identities and it was negotiated whether the interviewer was the anthropologist or the medical doctor depending on the topic. For example, when some general practitioners were uncomfortable with some questions about their practice with patients perceived as culturally different or they felt doubts about their answers, they usually added a remark about their non-expertise of the topic in comparison with the alleged interviewer's expertise: 'But you know better, I am not an anthropologist' or 'I do not know if I can talk about this, I am not an anthropologist'. With these kind of statements during the interviews, the predominant role as general practitioner is outweighed by the anthropologist's one, as a certain discomfort is made explicit about the fact of being interviewed by someone that is not an equal but someone who may judge from a different point of view. When the interview revolved about other aspects of healthcare practice, such as the organisation of work or working relationships, the colleague-physician identity came back into scene, and the suspicion that had arisen with questions about cultural aspects –considered outside of the healthcare professional realm– disappeared, and so also did the anthropologist identity. By delineating the limits of the researcher's identities, general practitioners are also establishing the limits of what is considered their realm of practice and the boundaries of their professional role. Suspicion about being assessed in a domain that is outside professional expertise is part of the affective economy that establishes the limits of professional roles. Uncomfortable emotions did not appear frequently when talking about medical problems or when using a language that physicians and nurses recognise as their own. However, discomfort arose when

symbolically surpassing the physician's role boundary. I have to note here that suspicion or unease were emotions that negotiated the boundaries of the professional role during the interviews with general practitioners, but these emotions took different shapes when talking with nurses or administrative staff: there, the interviews were mediated not only by my dual role but also by the different hierarchical position we had at the healthcare centre. For example, the administrative workers I interviewed did not differentiate between my roles as physician and anthropologist but tended to identify me only as a physician, and they did not make remarks about anthropology during the interviews.

Another event that brought to the fore my role as an anthropologist was the moment I asked nurses and physicians to allow me to observe in their consulting room. Even though the staff were very supportive during the presentations I gave at the staff meetings and during informal conversations at the coffee room, some of the nurses and physicians did not allow me to accompany them in the consulting room. Those who denied access to their consulting rooms gave different reasons: the most frequent being lack of time to introduce me to every patient and the disturbance it would create. Confidentiality was another reason to deny access to the consulting room, but it was not as frequently used as the lack of time. Albeit the multiple ethical clearances, the membership to the group studied, and the general willingness to participate in the research by most of the members of the staff, there were some spaces – some consulting rooms – that remained closed to the ethnographer. Some of the nurses and physicians who refused to allow participant observation in their consultations accepted to be interviewed and participated in the sessions I organised at the healthcare centre, so it was not a complete refusal to participate in the research. Yet the reasons they gave to deny participant observation during their consultations seemed quite feeble to me and showed some kind of mistrust towards me as an anthropologist and towards the research itself. A mistrust that shows the conceptualisation of the consulting room as a private, intimate space where there is no place for an external observer, even if that observer may contribute towards a reflexive understanding of clinical practice. The consulting room can be open to the eyes of someone else – as is the case with students, nurses, or during physician's training – but it seems that it is the gaze of the social scientist that perturbs the most with respect to confidentiality. Again, it was the biomedical ethical mandate – or its interpretation – that defined the anthropological research realm. As Aline Sarrandon-

Eck (2009) notices, it is the 'hard' sciences' framework that is used as a reference to evaluate the methodology and the realm of social scientists' research in healthcare. The reticence to share clinical practice with an observer shows the limited value given to social science research by healthcare professionals.

## **2.5 Confidentiality Dissonances II: The Desk**

David Mosse (2006) argues that while the intractable problem of access to closed organisational worlds is solved through membership of the communities we end up studying, the problem of exiting the community in order to have the required analytical distance is left unresolved. Mosse notes that rearranging fieldwork is the challenge for anthropology now: 'first, how fieldwork relations shape writing, and second, in how writing now alters relationships of 'the field' (2006, 936). I would add that in the case of those medical anthropologists with a dual role, the later becomes crucial as it can jeopardise subsequent professional relations. Following Mosse, for the anthropologist researching in the professional world,

'the relationship of the field persists, the capacity to exit through writing is in question, and ethnographic representations have become unavoidably part of the world that is studied. When desk collapses into field, something important has changed in the structure of ethnographic practice' (2006, 937).

The personal and professional relationship with the research subjects transcends the period of fieldwork and brings the possibility of self-censorship in order to protect the research subjects' confidentiality. Adler and Adler (2000) explain self-censorship as caused by different factors, among which the main one is the loyalty of the researchers to the research subjects and what they call "betrayal-anxiety" (2000, 170; quoted in Sarradon-Eck 2009). How to weight up loyalty to the research subjects and the respect for confidentiality with the necessary distance not to cloud the analysis is one of the challenges of the writing up process.

During this process, I aimed to distance myself from the social and professional relationships from fieldwork. I moved to another city and, despite keeping in touch with some colleagues, I limited my contact to a minimum. Yet, eventually I felt the need to share with my closer colleagues some of the doubts that haunted me when analysing the fieldwork materials: I was seeking for their approval of my analysis as a means to reduce my feeling of betrayal. I also shared these concerns with my

anthropologist colleagues, seeking to share similar experiences in their research practice and how they had addressed them. Debates about collaboration and different ways of anonymising the research arose when I brought up my “ethical anxiety” and disloyalty in the conversation. However, I still struggle with some questions about the use of some materials and I am worried about the reception the research results will have among the research subjects. It is not that I am revealing horrible secrets or portraying my colleagues in a harsh way, but I am conscious that there are some sensitive topics that the ethnography will explicitly bring up that not everybody will be happy to hear. Actually, that is the purpose of anthropology, to explore the taken-for-granted ways in which individuals make sense of their world in an inter-subjective way. The problem is that the taken-for-granted is therefore hidden and not everybody may agree with the interpretative account made from an anthropological point of view. Possibly, these concerns about the reception of their ethnographic account are similar for other anthropologists who do not have a dual role. Yet, I would suggest that there is something distinctive about doing research in those professional institutions the researcher belongs to in the way the feelings of betrayal and belonging interfere with the writing process, as ethical dilemmas or self-censorship. If this is the case, we should consider why that ethical scrupulosity is not applied in other areas of research.

## **2.6 Concluding Remarks**

Focusing on the role duality and the different positionalities during fieldwork, I reflect on the emotionality connected to the symbolic boundaries between both roles and the ethical tensions that underpin these emotions. “Ethical anxiety”, duplicitousness and betrayal are feelings that came up during my fieldwork and writing process, and I suggest that by analysing when and from which ethical tensions these emotions come from, we can draw the boundaries between the role as anthropologist and the role as physician.

I have not given any answer to these questions or how to deal with these emotions, but simply open the possibility of thinking about ethical issues from the perspective of the emotions they bring up and relate them to the difficulties of collaboration between different disciplines. One of the questions brought up by this reflection on how to conduct research among colleagues is how to make the research more collaborative in



cases where there is an epistemological incompatibility, as is the case of biomedicine and anthropology. While some healthcare workers were suspicious of qualitative methods and doubted their validity, other healthcare workers were curious and sought to reflect together about everyday practice from a different framework from medicine. Still, they differentiated between the roles of the research subjects and the researcher as this quote from an interview with a physician shows: ‘now you are not longer one of us, practitioners, now you belong to the group of those who conceptualise what practice is about’.

### **3. Thesis Structure**

As I have pointed out in the introduction, this thesis investigates the representations that primary healthcare workers hold about Gitanos and how these representations are mobilised in the encounters they have with Gitano patients in clinical settings. Similarly, at the encounters between Gitanos and healthcare workers it is possible to investigate the interrelations between social representations and institutional configurations in which these encounters are nested. Therefore, this thesis is divided in three main ethnographic chapters, each one focusing on the practices at a different place at the primary healthcare centres. Each of these chapters is divided in two main sections: the first one focus on the representations and configurations while the second section investigates the practices.

In the first chapter I provide some background information about Gitanos and Roma and about the public healthcare system in Spain. First, I analyse the relevant published literature on Gitanos and health, including institutional reports and public health surveys. Secondly, I present the broader cultural repertoires about Gitanos, looking at the historical and the institutional processes in which those repertoires are embedded. In the second part of the chapter, I provide some background for the public Spanish healthcare system and the current reconfigurations and challenges that it is going through. Finally, in last section I give some relevant information about the public primary healthcare centres where I conducted research, as well as the neighbourhoods where they are located.

As a prologue to the ethnographic part of this dissertation, the section Walls that Talk invites to enter the healthcare scenario through a selection of pictures from the doors of the primary healthcare centres. Primary healthcare is the access door to the healthcare system and the actual doors of the primary healthcare centres display messages that are worth analysing.

Chapter two investigates the practices at the primary healthcare centres' admission desks, how these practices are structured by the legal framework that regulate access to healthcare and the different ways this framework is interpreted in the encounters with Gitanos. In these practices, different ideas of citizenship are enacted in relation with cultural difference, which often helped to justify practices of exclusion based on the construction of Gitanos as illegitimate patients. I analyse how different understandings of the administrative clerk' professional role as well as structural constraints such as the scarcity of resources shape the practices at the admission desk.

Chapter three focuses on the clinical encounters between doctors/nurses and Gitanos. In this chapter I explore the different mechanisms set in motion to identify Gitanos and the practices that these identifications give rise to at the consulting rooms, in order to unpack the meanings and uses of cultural difference in that site. Differently from the admission desk, at the consulting room gitanos' difference revolves mainly about the unruliness of Gitanos in regard with way they take care of their body, be it the physical or the social body. This chapter analyses the different practices in which these representations are enacted.

Chapter four moves away from the primary healthcare centre and it is based on the healthcare van that provides care at an informal settlement. First, through the analysis of the institutional configurations that brought to light a service such as the van, I examine the humanitarian logic that underlies the healthcare van's creation, as well as the entanglements between negative stereotypes about gitanos and expert's knowledge. In the second section of the chapter, I explore the practices at the healthcare van as an interstitial service that challenges the logics of compassion and repressions that underlined its creation.

Finally, in the conclusion chapter, I provide a summary of the main ideas elaborated throughout the thesis in relation with broader anthropological debates.

# Chapter One: Background

## 1. Gitanos in Spain

### 1.1 Biomedical Research: Between fatalism and exclusion

The number of Gitanos living in Spain is estimated to be between 1,8 and 2,1% of the Spanish population, which means around 725 000 and 750 000 people (FSG 2009; MSSSI 2012). These are the institutional figures used to design the policies and intervention programmes aimed at the Gitano population. Other sources estimate a higher number of Gitanos living in Spain (in between 800 000 and one million) (FOESSA 2008, 2014): the difference in the estimation may be due to the ethnic identification method that the different agencies use in their surveys. Still, Spanish Gitanos are considered one of the most numerous Romani populations in Europe: some authors suggest that Spain is the second European country after Romania where more ‘Roma’ live (Liégeois 1995; MSPSI 2011). Spanish Gitanos live all over the national territory but there are some regions with a higher proportion of Gitanos, such as Andalusia, where it is estimated that one third of the Gitanos live. Similarly, Gitanos are represented in all the socioeconomic strata, but they are overrepresented in the lower strata, with some of them living in marginal conditions.

Spanish policies regarding Gitanos have adopted the European framework on Roma and thus, Gitanos are considered part of the European Roma minority and therefore in most of the official documents, when translated into English, they are referred to as Spanish Roma<sup>5</sup>. Despite their shared history of segregation in European societies,

---

<sup>5</sup> The EU definition of Roma has gone through different modifications. This is the one from 2011: “an umbrella, which includes groups of people who have more or less similar cultural characteristics, such as Sinti, Travellers, Kalé, Gens du voyage, etc. whether sedentary or not; around 80% of Roma are estimated to be sedentary (SEC (2010)400).” Therefore Roma is also the ethno-political category used

Roma minorities in Europe differ widely between different groups and are usually described as ‘a mosaic of small diverse groups’ (Liégeois 1995). It is because of this heterogeneity among and between groups that the use of the homogenising ethno-political category “Roma” in the European policy realm and beyond raises some concerns among scholars (Surdu and Kovats 2015; Vermeersch 2012; Sigona and Vermeersch 2012). It is an interesting debate that goes beyond the focus of my research. Nevertheless, the tension of the use of ‘Roma’ as a unitary category is also reflected in biomedical research about Roma: if Roma is a constructed political category, the question is to what extent the health issues found in one Roma group could be extrapolated to other Roma groups.

In the last decades, the number of published biomedical articles on the topic of Roma and health has increased significantly in Europe. This new focus of attention is part of a general research trend on ethnic health and migrant health issues in relation to social determinants of health that coincided with the expansion of the EU to include central and Eastern Europe in 2004 and 2007 and the subsequent construction of Roma as an ‘European issue’ (Magazzini and Piemontese 2016). In order to have an understanding of the latest insights on the topic in the Spanish context, Ferrer’s systematic literature review is a good starting point. He found that there were 96 medical articles related to Gitanos’ health issues whose authors were working in Spain (Ferrer 2003). This represented a larger number in comparison with the research published on Roma health in other European countries (Hajioff and McKee 2000). However, the topics that these research articles investigate provide only partial information about the Gitanos’ health status: most of the articles were about genetic and congenital diseases (Ferrer 2003, 4): some of them confirmed the Asiatic origin of Gitanos, and others built on notions of endogamy among Gitanos as a causal mechanism of disease. Transmissible diseases were the second most common research topic and despite some of the articles taking into account social determinants of health; most of these articles depicted Gitanos as a population at higher risk. In fact, Ferrer’s conclusions in the literature review state it quite clearly:

---

by the European institutions to refer to Gitanos (Kalé). Roma is also the term used by Spanish institutions when translating policies and other documents related to Gitanos into English. Interestingly, The Spanish versions of these documents refer to migrant Roma as “*gitanos migrantes*”.

‘The Spanish gypsy community constitutes a health risk group due to ethnic and genetic factors. Moreover, they also have strong social inequalities in health related to mortality and morbidity in transmissible, chronic and environmental diseases due to socioeconomic and cultural factors, as well as to insufficient access to and use of health services’ (Ferrer 2003, 2)

On their part, Steve Hajioff and Martin McKee, after reviewing the literature on Roma health (published in English), conclude that there is little information on the health needs of Roma populations and stress that research’s focus on transmissible disease and family planning underlies the fears of majoritarian populations towards Roma (Hajioff and McKee 2000, 868).

Most of the biomedical research conducted in Spain about Gitanos uses the tropes of exoticism and marginalisation (Marushiakova and Popov 2011) to frame both the research questions and the subsequent analysis. The standard fashion to talk about Gitanos in biomedical articles is to begin with the classical reference to Roma and Gitanos as the largest European minority to continue by informing the readers about the Indian origin of Gitanos and their arrival to the Iberian peninsula in the fifteenth century, perhaps then adding some information about the genetic and linguistic research that proves the Indian origin. The next usual step is to refer to the historical persecution and marginalisation Gitanos have suffered in most European countries, as well as the on-going marginalisation of Roma groups. Depending on the article’s research topic, the authors may add what are considered cultural characteristics of Gitanos, for instance the respect for their elders, or their Gitano pride (some examples could be Garcia de Cortazar et al. 2009; Peinado-Gorlat et al. 2015; García et al. 2000). The use of these two tropes (exoticism and marginalisation) partially account for the recurrent research both on genetic-congenital disorders and transmissible diseases; the former alludes to the exotic origin and endogamous character of Gitano culture, while the latter represent the consequences of unsanitary conditions and marginalisation. Similarly to research on Roma and health in other contexts (Van Cleemput et al. 2007), fatalism is one of the cultural traits ascribed to Gitanos, which is used to some degree as an explanation for their differential access to health facilities (García et al. 2000; Ramos-Morcillo et al. 2014; Ferrer 2003; MSC and FSG 2005).

Despite the authors’ good intentions when investigating the health inequalities that Gitanos face, after reading these articles, one is left with the impression that you

learned quite a lot about very rare diseases but very little about Gitano's health status or their health needs. With the exception of some interesting articles (such as La Parra, Gil-González, and Jiménez 2013; Carrasco-Garrido et al. 2011) I had the feeling that I was reading the same narrative over and over, as if it were a necessary condition to write an article about Gitanos, that ultimately just reinforced the idea that Gitanos are different from non-Gitanos and that their endogamic culture was responsible for their exclusion. However, when looking for health status or demographic data that I could use as background information for my research, I only found scattered data that was not enough to provide a relatively accurate picture of the health status of Gitanos in Spain. For example, there is no national data on fertility patterns among Gitanos (Campos Esteban, personal communication) nor Roma; there is only some data based on small studies with specific Gitano communities (Mitsuf Gallardo et al. 1997; Martín and Gamella 2005) that cannot be extrapolated to the general Gitano population (but which has sometimes been extrapolated or taken for granted<sup>6</sup>). Another relevant aspect that is missing in these articles is research on chronic health conditions in Gitano population from different socioeconomic backgrounds, an aspect that nevertheless has been covered by the institutional initiative of the Ministry of Healthcare.

Since the beginning of democracy Gitanos have gained certain institutional recognition: the 1978 Spanish Constitutional Act acknowledges cultural and historical differences within the national state and since then, Gitano culture is state-recognised. Institutional measures were put in practice at a national level as a means of recognition of Gitano culture, such as the "Gitano Development Programme" that started in 1989, the foundation of the State Council of the Gitano People in 2005 (Consejo Estatal del Pueblo Gitano) or the creation, in 2007, of the Institute for Gitano Culture. The Ministry of Health and Social Issues opened a research and intervention line in health promotion with Gitano population in the 2000s: a working group in which members of the State Council participate, as well as regional

---

<sup>6</sup> One example of how fertility data are extrapolated from one context to another is the Report on Health Promotion in Navarre for the World Health Organization (Pérez Jarauta, Goya Arive, and Merino Merino 2010). In the report they use the fertility data of a research conducted in primary healthcare centres in Andalusia from 1997 (Mitsuf Gallardo et al. 1997)

representatives. This national working group has been pioneer in producing reports and recommendations concerning Gitanos in healthcare and in coordinating the different regional experiences<sup>7</sup>. Acknowledging the scarcity of information and the “topic bias” of the biomedical research on Gitanos’ health, the working group managed to conduct in 2006 the first national health survey among Gitano population in Spain, and compare it with the National health survey (MSPS 2006). A second national survey has been conducted in 2014 and the data was published in 2016 (MSSSI 2016). Both surveys provide information about health conditions, lifestyles and use of healthcare, yet it is important to bear in mind their limitations: first, the information gathered in these surveys is self-reported data, so some responses may be conditioned. Secondly, due to the first limitation and other methodological issues, the National Health Survey is not validated for chronic diseases and lifestyles. Therefore, both surveys are good attempts at providing information about the health status of Gitanos and, despite their limitations, they are the only sources we have at a national level.

Among the survey’s findings was that Gitanas<sup>8</sup> report worse health than non-gitanas (Payas) and suffer more from depression, obesity and migraine (MSPS 2006, 148; MSSSI 2016, 141). While there are no differences in reported health status between young Gitanos and non-gitanos (Payos), differences appear at older ages with elder Gitanos reporting worse health than their Payo counterparts. Tobacco consumption among men and unhealthy diet patterns are other aspects signalled in both surveys. Regarding the use of the healthcare facilities, it is interesting to note that there were no differences between Gitanos and Payos in the use of emergency rooms and primary healthcare services. Relating to the use of services, the only difference found between both populations was that Gitanas have less mammography screenings than Payas, which in itself is not very interesting information from a biomedical point of view as the utility of mammography breast cancer screening programmes is itself controversial. Another topic is dental health where Gitano children are less likely to

---

<sup>7</sup> On top of the national inclusion strategies, there are five regions that developed regional inclusion strategies, too. From these regional strategies, Navarra has been the example to follow in health issues.

<sup>8</sup> Gitanas is the female of Gitanos. Similarly, Payas is the female of Payos, that is the way Gitanos refer to non-gitano people

have attended a dentist, and Gitano adults are less likely to have had dental work such as fillings.

It is important to note that the data obtained in these surveys helped in building the health area of Spanish National Inclusion Strategy for Roma population<sup>9</sup>. Thus, to reduce the smoker rate among Gitanos, or to increase the number of Gitanas who use preventative services, become specific health targets of the inclusion strategy, while also proposing measures aimed at reducing inequality and addressing cultural diversity in the National Healthcare System. However, when comparing the results obtained in the 2006 survey with those of 2014, there are no significant differences: there has not been a reduction in the health inequalities that Gitanos suffer. Gitanos' perception of their own health has not improved, nor has their life expectancy, which is approximately seven years less than the general population (FSG 2009). In light of these result, the authors of the last survey report called into question the interventions and policies that have been implemented; not only those interventions directly related to healthcare but also other measures that may indirectly have an effect on health status (employment, housing...). They suggest that an analysis and evaluation of the policies and programmes is needed in order to implement measures that effectively reduce Gitano inequalities in health (MSSSI 2016, 4). In this sense, the survey report, albeit in a mild tone, gathers all the voices that in recent years have challenged 'the myth of the Spanish model of Roma inclusion' (Maya Ovalle and Mirga 2014, see other critiques Bereményi and Mirga-Kruszelnicka 2012; Beluschi Fabeni, López López, and Piemontese 2014).

## **1.2 Migrant Roma**

Interestingly, the current National inclusion strategy makes explicit mention of European Roma living in Spain:

---

<sup>9</sup> Spain developed, as have other European countries where Roma population live, a National Inclusion Strategy within the European inclusion strategies framework to be implemented between 2012-2020. These strategies tackle four areas: education, employment, housing and health. In its English version, the Spanish National Inclusion Strategy translate Gitano into Roma, that is the reason why I keep Roma here, despite Gitanos are the main recipients of this regulation, and Roma are included as "migrant Roma"



‘The Strategy will pay special attention to EU Roma citizens residing in Spain, or other Roma persons originating from third countries. The focus on work will be inclusive, to the extent that participation in measures and actions aimed at Spanish Roma will be extended. Likewise, where circumstances allow, specific measures and action will be rolled out in order to promote and ease social inclusion.’ (MSSSI 2012, 28)

Romanian Roma migration to Spain started thirty years ago, not as an isolated phenomenon but it was part of a mayor trend of Romanian citizens migrating to Spain. The first period dates from the nineties: in the wake of the end of socialist systems; Romanian Roma arrived to Spain, as well as to other European countries, as asylum seekers (Gamella 2007; Reyniers 1995). The lifting of visa requirements for Romanians travelling through the Schengen Area in 2002 and the subsequent entry of Romania into the EU in 2007 made the entrance of Romanian citizens more flexible, albeit the moratorium to be granted the right to work. The number of Romanian migrants increased in Spain during those years and in 2007 they became the largest migrant group in the country (Viruela Martínez 2008). Spain became a country where the possibilities to find a job in the informal market were higher than in other countries in the EU (Viruela Martínez 2008). A positive representation of Romanian migrants, compared to other migrants, emerged in the Spanish social imaginary. Viruela Martinez (2008) signals seriousness, discipline, initiative and responsibility as some of the main characteristics that employers and the wider social context attribute to Romanian migrants. The fact that Romanians were mainly employed in supplementary jobs and they did not compete directly with nationals for jobs helped create this positive representation (Pajares 2007).

However, the positive representation of Romanian migrants in Spain does not extend to all of them: Romanian Roma are not included in this social imaginary. When Pajares (2007) enumerates the negative stereotypes linked to Romanian migrants, being Romanian Roma is one of them, as well as participating in organised crime or prostitution. Romani migrants elicit similar negative stereotypes as the long-time settled Gitanos. In Bereményi’s (2012) research on public schools, he shows how the positive connotations of the national category Romanian are subjected to the negative stereotypes of the ethnic category Roma, denying the identification of the later with the experiences and aspirations of the former (Bereményi 2012, 1625).

This clear distinction between Roma and non-Roma Romanian migrants was also found in a research conducted in public healthcare facilities in Madrid (Spain). Seoane and Portero (2006, 72) found that the positive representation of eastern European migrants is echoed in the discourse of healthcare staff. In this study, Romanian patients are described as similar to Spaniards and therefore non-conflictive. Nevertheless, the exceptions to this positive representation are Romanian Roma, who are considered problematic patients, unable to comply with the institutional rules. Healthcare staff also uses the narrative of unruliness to describe Spanish Gitanos, and they use it as a benchmark to compare other migrant groups against (Seoane and Portero 2006, 75). However, whereas in some migrant groups the unruliness is perceived as a consequence of their novelty and not being familiar with the local healthcare system, in migrant Roma and Gitanos it is considered an essential cultural trait.

The estimated number of Eastern migrant Roma (from Romania and Bulgaria) living in Spain is between 50 000 (MSSSI 2012, 12) and 170 000 (López Catalán 2012). Not all of them live in the same conditions; some of them live in standard housing and have regular jobs whereas most of them live in overcrowded houses or in informal settlements on the outskirts of big cities. Those who live in better conditions tend not to be associated with the negative stereotypes linked to Gitano culture. As Pajares (2007) argues, those who are considered Romanian Roma (*Gitanos rumanos*) are those who are “distinguishable”, those whose adaptation and survival strategies are visible, such as begging in the streets or living in informal settlements. From 2002, with the increasing number of Romanians arriving in Spain, migrant Roma settled in abandoned buildings and deprived areas in the peripheries of several Spanish cities. Depending on the market situation, they rented affordable houses, or made their own homes out of discarded materials in wastelands (López Catalán and Aharchi 2012; Gamella 2007). But it was especially after the 2007 enlargement and the mass evictions from other European countries that migrant Roma became a public issue both in the Spanish media and in the political agenda (López Catalán and Aharchi 2012; Magazzini and Piemontese 2016; Beluschi Fabeni, Gamella, and Gómez Oehler 2015).

There are some previous exceptions of migrant Roma attracting institutional and media attention, at least at the local level. I focus here on the origin of the settlement

where the healthcare van works. In Madrid, one of the first settlements from 1999 called Malmea became highly mediated and its eviction by local authorities triggered the implementation of a special integration programme exclusive for migrant Roma (Gamella 2007). Malmea was an urban area located in the Fuencarral district, in the north periphery of Madrid. Its name is believed to come from the previous inhabitants of the area, mostly Spanish migrant workers who came to the capital from rural areas in the aftermath of the civil war and settled down in the periphery of the city in shacks and makeshift dwellings. During the sixties and seventies, this area was upgraded following one of the numerous plans to ‘eradicate shantytowns’<sup>10</sup> and it became a ‘*poblado dirigido*’, which means that the owners built their own houses under the supervision of institutional architects. Malmea may be the surname of one of these migrant workers who self-built his house under the auspices of the architects of the Franco dictatorship (Alpuente 1999).

Some Roma families who arrived to Madrid in 1989 settled down in one of the wasteland of the area, surrounded by a dumpsite. They became a ‘public issue’ after UNICEF and the ombudsman denounced the unsanitary and precarious living conditions of the children living at the settlement<sup>11</sup>. Unfortunately, one week after UNICEF’s public complaint, a two year-old child died in a fire caused by a candle inside a tent in the settlement. Thus, the local and regional government were prompted to act in order to solve ‘the Malmea problem’: it was a case of social emergency because it was inadmissible that children were living in those unsanitary conditions. Besides, if the settlement became permanent, its existence would have an impact on the new urban planning for the area. So the settlement should be displaced to another, less conflictive location.

---

<sup>10</sup> I delve into the housing policies aimed at Gitanos in a further section of this chapter.

<sup>11</sup> The UNICEF and ombudsman complaint already highlighted some paediatric health problems attributed to the unsanitary conditions the children were living in. They enumerate gastrointestinal and respiratory conditions, scabies and lice. However, these institutions did not proposed to tackle health problems with a healthcare unit but they proposed upgrading the settlement or creating places to host the migrant families in better conditions. The complaint drove forward an agreement between the public healthcare and the Red Cross to send a healthcare team to vaccinate the children. (from [http://elpais.com/diario/1999/02/25/madrid/919945464\\_850215.html](http://elpais.com/diario/1999/02/25/madrid/919945464_850215.html))

It is interesting to note the media's handling of the 'Malmea issue', a reflection of how the lack of knowledge of these 'new Roma' was framing the political and institutional discourse. The regional government repeatedly alleged Eastern Roma's nomadism<sup>12</sup>, as well as the possible pull-effect that upgrading the settlement would have, as the reasons not to intervene. On their part, the press and political opposition drew on the Italian and French camp examples to demand the regional government's intervention. Nomadic people, a term used in some European countries (*Nomadi* in Italy or *gens du voyage* in France) to institutionally refer to Roma, was initially chosen to talk about the Romani migrants from the settlement, as the name given to the project clearly states (integral intervention project for migrant nomads). It seemed that creating some 'provisional shelter for migrant nomads'<sup>13</sup> was an appropriate measure that lived up to the European standards and gave a response to the 'social emergency' that the Roma families presented. Hence, the Roma families who lived in the settlement were relocated in three camps managed by two NGOs and funded by the local, regional and national government.

The families living in the camps had to sign a contract of rights and duties with the institution, in which the prohibition to beg with children or the obligation to school them were stated. From the initial and exceptional programme, called ACUMA – which in Romanian means now – a new plan to 'provide more stable alternatives to the migrant nomadic collective in our territory' (BOE 2001, my own translation) was envisaged and developed. This was the birth of the APOI project, whose aim was to help the progressive integration of those migrant nomads who were willing to. The

---

<sup>12</sup> A statement to the press from the social services city councilor at the time, Esperanza Aguirre, is illustrative of alleging nomadism while acknowledging ignorance about Roma's migration: 'we want to know their (Roma) needs and we want to know if their intention is to settle down in Madrid because social services do not intervene in the same way with those who plan to be here temporarily' (Aguirre, 1999, my own translation) available online at [http://elpais.com/diario/1999/02/18/madrid/919340659\\_850215.html](http://elpais.com/diario/1999/02/18/madrid/919340659_850215.html) "Queremos conocer sus necesidades y saber si su intención es quedarse en Madrid porque no se realiza la misma intervención social con alguien que está de paso"

<sup>13</sup> This is the way that the official Spanish bulletin described the settlement. Source BOE 179 (2001) available online at <https://www.boe.es/boe/dias/2001/07/27/pdfs/A27635-27637.pdf>

camp located in the southern outskirts of Madrid, close to the local dumpsite<sup>14</sup>, was conceived to be a temporal settlement for people passing through the city, and paradoxically it became the germ of a stable irregular migrant Roma settlement in Madrid. When in 2006 there was a restructuring of the APOI project – which in those years became open to migrants in general, no longer being a project specific for migrant nomads (aka migrant Roma) – the legal camp in the south outskirts of Madrid was dismantled. Those families who were part of the project were moved to the other camps in the northern periphery of the city, and those whose time in the project was finishing, moved to other accommodations, such as the nearby informal settlement that was to remain until today.

In terms of biomedical research, little is known about the health status of migrant Roma in Spain apart from few medical articles about infectious diseases outbreaks (Luna Sánchez, Rodríguez Benjumeda, and Ortega Sánchez 2013). However, there is an exhaustive study on Roma, their access to healthcare and health status, conducted by a team of anthropologists and commissioned by the Catalanian regional healthcare service (Rodríguez García and San Román Espinosa 2007). In this report, Meritxell Sàez Sellarès and Oscar López Catalán (2009) studied the migrant Roma population in Catalonia and contextualised their access difficulties, health status and healthcare-seeking behaviour within the broader structural and migratory framework. Among other interesting points, they highlight the arbitrariness in obtaining documentation that grants access to healthcare, the similarities with Payos in their perceptions regarding health and disease, and the communication difficulties they find during clinical encounters (2009). Sàez Sellarès and López Catalán note that the communication difficulties at the healthcare centres ‘are not insurmountable, neither are generalisable for all the migrant Roma population and neither are migrant Roma exclusively responsible for these difficulties’ (2009, 238). To some extent, migrant Roma (as long as they are identified as so) and Gitanos share the similar negative representations in the Payo’s social imaginary. In fact, in the Spanish context, migrant Roma are usually called *Gitanos rumanos*, and they may find similar difficulties in

---

<sup>14</sup> The location of this camp was controversial and some politicians from the regional government opposition contested the location as inhabitable and isolated from the city.  
[http://elpais.com/diario/2000/07/25/madrid/964524268\\_850215.html](http://elpais.com/diario/2000/07/25/madrid/964524268_850215.html)

accessing public services as Gitanos. In what follows I explore the main cultural repertoires regarding Gitanos in Spanish wider society to understand how these representations can influence the practices at the primary healthcare centre.

### **1.3 Cultural Repertoires in Regard to Gitanos**

In 1990, Tomás Calvo Buezas published his book “*España Racista? Voces payas sobre los gitanos*” (Racist Spain? Non-Roma voices about Roma). It was the product of his research into the representations of Gitanos among school children aged between 10 and 16 years old. Through a survey and free texts from more than one thousand children Calvo Buezas analysed the collective representation of Gitanos in Spain and he states:

‘the spirited testimonies of these children and teenagers will reveal the entanglement of values and beliefs, both in the paradigm of egalitarianism and in the firm anti-Gitano prejudice. *Children –similarly to drunks- say what adults publicly keep quiet.* Hence the high testimonial value of these non-Gitano “voices” about the Gitanos’ (1990, 28, my translation, emphasis mine).

Despite the fact that more than twenty-five years have passed since the publication of this book, anti-Gitano prejudice still prevails in contemporary Spain (MSPSI 2011; Fernández Garcés, Jiménez González, and Motos Pérez 2015). However, I chose this quote for a different reason, which I have emphasised in italics. Calvo Buezas (1990) highlights the value of the children’s narratives, as their speech is less inhibited than that of adults. He presupposed that the same research with adults would entail more difficulties in the sense that adults moderate their responses to not appear racist. Maybe that kind of self-censoring can be expected when researching any other ethnic group, but the prejudice against Gitanos and Roma is so pervasive and commonsensical in Spanish society that comments that would be inadmissible if made about any other ethnic group or collective are very well tolerated. As Fernández Garcés et al. describe, ‘the anti-gitano prejudice is treated as third-class importance racism: as a racism that does not need to be socially or politically sanctioned’ (2015, 10). The same authors argue that anti-gypsyism is an European phenomenon which has become more pronounced due to the economic crisis and the rise of populism (2015, 12), as some authors have pointed out (Trehan and Sigona 2009; Stewart 2012). Still, the latent (or low intensity) anti-gypsyism is a necessary condition without

which the violent incidents that have taken place all over Europe would not have been possible. Hub Van Baar coined the term ‘reasonable anti-Gypsyism’ to refer to:

‘A widely supported movement among non-Roma seeks retaliation under the pretext that the Roma frequently exhibit undesirable behaviour. The argument goes that you are rightfully entitled to act against the Roma and treat them differently, because they cause inconvenience, indulge in criminal activity and can generally be expected to cause trouble. It is not “we” but “they” who violates rights and fail their duties’ (2014, 29).

The idea that Gitanos cause inconvenience and trouble is pervasive in wider Spanish society. Gitanos are considered to be people with whom it is better not to be close. However, whereas Van Baar makes emphasis on the securitarian measures that reasonable anti-gypsyism entails, I argue that reasonable anti-gypsyism takes a distinct form in the Spanish context, moving the focus from security to conviviality issues. The historical processes of segregation and assimilation and the multiple programmes and policies grounded on the shared idea that Gitanos are innately unsuited to living among non-gitanos are part and parcel of the Spanish version of ‘reasonable anti-gypsyism’. Reasonable anti-gypsyism in Spain is a matter of conviviality: their “unruliness” makes them unable to live among non-Roma Spaniards (*payos*), therefore they need to live in special places just for them.

Giovanni Picker and Gabriele Roccheggiani, drawing from Foucault’s ideas about ‘the abnormal’ (Foucault 2003a), argue that the representation of Roma as not fitting the norms of the majority (and thus being considered socially deviant) is based on ‘historically rooted representations of Roma oscillating between the poles of potential re-educability and potential dangerousness’ (2014, 185) They also maintain that the norm that structures Roma’s social deviance is sedentariness (2014, 187). In Italy, Roma are called ‘nomadi’ and policies tackling Roma are framed under the idea that they are nomads. The authors argue that ultimately this definition of Roma in opposition to sedentariness leads to an ‘ambivalent situation of inclusionary efforts in a stable condition of social exclusion’ (2014, 190).

In the Spanish case, representations of Gitanos also oscillate between potential re-educability and potential dangerousness, but nomadism is not the core principle organising ‘Gitanos’ deviance’. I argue that the norm against which Gitanos’ social deviance is measured is “compliance”; as unruliness is considered one of the main

characteristics of Gitano culture, it explains their inability to comply with the basic rules of conviviality and therefore Gitano policies are framed in terms of re-education to comply with major society's shared norms regarding sociability. It is Gitano's unruliness that makes them unable to live among payos while unruliness can potentially be re-educated through state intervention programmes. It seems that the Italian and the Spanish example differ on the norm to measure the degree of social deviance, but paradoxically they produce similar responses based on 'inclusive exclusion' (Picker 2012). Similarly to the Italian case, nomadism is also considered a Gitano cultural trait, but one that they progressively abandoned, partly due to the public housing policies aimed at them. Still, nomadism functioned as a feature that distinguished "new" migrant Roma from Gitanos, as the former were –and to some extent still are– perceived as nomads. In the wider social imaginary, the abandonment of nomadism is recognised as a sign of Gitano progress and to some extent, as a result of the inclusion strategies aimed at Gitanos.

Drawing from Canguilhem (1989), Foucault reminds us that 'the norm is not simply and not even a principle of intelligibility; it is an element on the basis of which a certain exercise of power is founded and legitimized' (Foucault 2003a). In that sense the Italian and the Spanish example are not that different, as I would argue that sedentariness is one aspect of the broader norm "compliance". The argument goes as follows: Gitanos were nomads but thanks to the state intervention they settled down, they are one degree further than Italian Roma (or migrant Roma) who are still "nomadic". However, Gitanos are still not able to live among payos due to their unruliness, therefore, more institutional programmes and interventions are needed to "integrate" them. Gitanos represent what Foucault refers to as 'the individual to be corrected' (Foucault 2003a), a figure that appeared in the eighteenth century whose abnormality was framed in the family and the disciplinary institutions. Foucault argues that the individual to be corrected is a figure fraught with ambiguities, as it is defined by its incorrigibility but still 'paradoxically, insofar as he is incorrigible, he calls up around him a number of specific interventions over and above the customary and family techniques of training and correction, that is to say, a new technology of rectification, of supercorrection' (Foucault 2003a). It is this relation between incorrigibility and re-educability that underlies most of the Gitanos' inclusion programmes and, to some extent, the pervasive reasonable anti-gypsyism. In what follows I expose an example of how the ideas of incorrigibility and unruliness as social



deviance are shaped in a medical article and in a charity flyer; and finally I discuss more in depth the spatial segregation of Gitanos as a consequence of their alleged rectifiable incorrigibility, which ultimately reinforces it.

The first example is an article published in a medical journal that presents the results of a survey conducted in a hospital in Barcelona. The main aim of the survey was to define the main difficulties in attending to Gitanos in comparison with migrant patients. The premise of the study was that Gitanos pose difficulties in healthcare centres and the authors aimed to understand where those difficulties come from. When describing the Spanish Gitano population they attend to, the authors state:

‘staff have occasionally expressed weariness due to the difficulties and conflicts in dealing with a Gitano group from the nearby neighbourhood of low socio-economic status hit by delinquency and drug problems. These Gypsies speak fluent Spanish, and have been residing in the area for around 40 years, initially in shacks, which were demolished and replaced by the local authorities with low-cost-flats. Continuous efforts are being made to upgrade this district’ (Ho and Cordovilla 2004).

This quote nicely summarises years of local housing policies that isolated Gitanos in substandard subsidised houses and how these policies are understood in terms of integration. As Paloma Gay y Blasco argues, these isolating housing policies were framed as inclusive and positive discrimination measures (Gay y Blasco 2016), which, as the article shows, has become the dominant narrative. The territorial delimitation and link between Gitanos and substandard housing is as obvious as is the link with illegal activities and delinquency. Gitanos are potentially dangerous but still the local authorities make efforts to upgrade their living conditions: they may be re-educable. However, Gitanos are presented as problematic from the beginning; healthcare workers have difficulties in their encounters with Gitanos and it is not because of their “newness” or language issues, it is in the conclusion that the authors make clear their stance on the relational issues with Gitanos that they explore in their research:

‘This study demonstrates that the staff generally experience more difficulties in professional-patient interaction with the Gypsy group than with migrant patients. These difficulties are not language or religion related, but mostly caused by the abiding cultural customs and values that the Gypsies possess. This leads to a rejection of socially shared norms, including hospital rules. Thus, this conduct provokes what the author feels as ‘being self-marginal’,

resulting in conflicts in a care provision which is equal, free and universal for all' (2016, 233).

For the authors, it is Gitanos' unruliness or unwillingness to comply with any rules, be they social or hospital rules, that makes them be marginal: it is their culture that marginalises them. In the article, there is a clear distinction between the rightness and good intention of institutional measures (the free equal and universal care, the social houses and neighbourhood upgrading) in contrast to the negligent and wilful behaviour of Gitanos. Healthcare is free and equal for all, as long as you comply with our rules; but as Gitanos question those rules, they can be treated differently, meaning being excluded from healthcare. However, it is not the healthcare workers who exclude Gitanos, they exclude themselves (as in the housing segregation) because they reject the socially shared norms.

The second example that illustrates Spanish 'reasonable anti-gypsyism' is a flyer from a well-known catholic charity (see below fig 1). The flyer gives information about the address and opening hours of the Caritas' clothing service in a city in northern Spain. But what is striking is that they differentiate between two categories of users: Tuesdays is the day for "people in general" (*gente en general*) and Thursday is the day for "Gitanos". The differentiation between "people in general" and Gitanos ultimately defines the latter as being something different to people, or at least a kind of people that should not mix with "people in general".

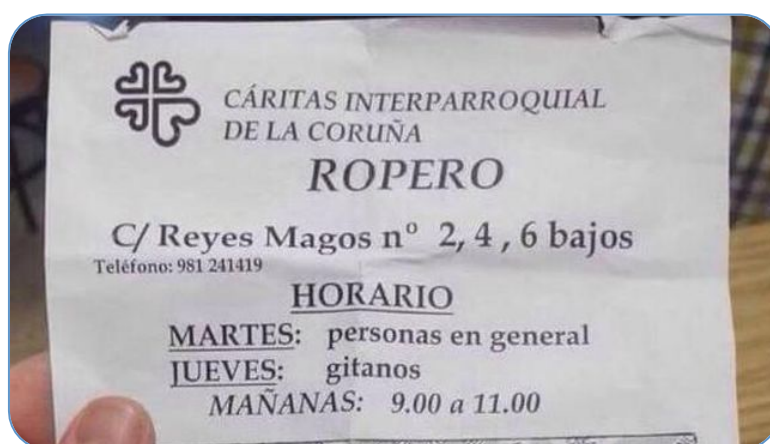


Figure 1. NGO flyer that sparked a polemic in the social media

The flyer does not only show how well tolerated or even expected anti-gypsyism is, but it also serves to identify one of the prevailing mechanisms to control Gitanos: to separate them from the rest of society on the grounds of their alleged capacity to cause trouble. From housing policies, schooling (Gay y Blasco 2016) or in charity work, the paradox described by Picker (2012) of ‘inclusive exclusion’ is put in practice with Gitanos.

## **Housing**

In our society Gitanos represent a social minority whose education, housing, healthcare, jobs and economic characteristics are, in most of the cases, those of developing countries<sup>15</sup> (del Real Llorente, Pellegrini Belinchon, and del Molino Anta 2000)

The opening quote is from another medical article about the benefits of breastfeeding for Gitano population. As we can deduce from the quote I chose, promoting breastfeeding among Gitanos was grounded not on the general benefits on which breastfeeding promotion to the general population is based, but on the extra benefits it entails in developing countries or “contexts”. In the article, Gitanos are compared to people from the poor south on the basis of their living conditions. Despite the fact that Gitanos live among us, through this dissertation I will argue that they are perceived as ‘people from other places and other times’. The places where Gitanos live, or where most of the payos think they live, are crucial in structuring the representation of Gitanos as out of place and out of time. A representation where ideas of progress are intertwined with cultural representations of Gitanos’ unruliness and the need to keep them apart from the rest of society while trying to integrate them. However, the places where Gitanos (are believed to) live are the product of successive urban planning programmes that left them apart and subsequent Gitano-specific housing projects.

First, housing is similar to the previous examples I provided of reasonable anti-gypsyism connected to conviviality issues. It is taken for granted that living close to

---

<sup>15</sup> En nuestra sociedad, la población gitana representa una minoría social con unos niveles de educación, vivienda, sanidad, trabajo y economía propios en gran parte de los casos de los países subdesarrollados.

Gitanos is problematic and not the first choice for most of the Spanish population. The data from the last survey on discrimination, dating from 2013, shows it clearly: when asked about who you would mind having as neighbours, Gitanos was the group that more respondents minded living with. 6,3% answered that they would be very bothered about living with Gitano neighbours, 12% answered that they would be quite bothered, 18,2% would have some concerns about living close to Gitanos, and 14,3% would be a little bit concerned. In total, 50,8% of the people asked had some concern about having Gitano neighbours (CIS 2013). This survey was conducted by the CIS (Centro de Investigaciones Sociológicas / Centre for Sociological Research) and the sample was national. These data show how permissive Spanish society is with regard to anti-gypsy prejudice, which makes it reasonable to state that you do not want to live close to Gitanos or Roma. If we bear in mind the methodological limitations of surveys in terms of asking about controversial subjects, and consider that maybe even more people may reject Gitanos despite not replying to that effect in the survey, then Van Baar's idea of 'reasonable anti- gypsyism' resonates. As an anecdote, I would add that Daniel Laparra, one of the sociologists in charge of analysing the data from the Roma national health survey, during the presentation of the preliminary results of the last survey, and talking about racism against Gitanos and Roma in Spain, made explicit mention of Tomas Calvo Bueza's comments about the results of the perceptions about discrimination survey: even for the CIS survey, a survey with questions that everybody can see the right answer to – Calvo Bueza affirms – people keep on answering that they do not want to live with Gitanos<sup>16</sup>. Maybe the 'right answer' in the Spanish imaginary is the rightful refusal to live close to Roma and Gitanos.

It is not only surveys that have found these cultural repertoires in regard to Gitanos. Paloma Gay y Blasco also noted that the idea that nobody wants to live close to Gitanos is taken for granted by those social workers who are in charge of relocation programmes (among other duties), in the settlement where she conducted fieldwork in

---

<sup>16</sup> From my field diary, notes on the presentation of the preliminary findings of the Roma health national survey. March 2015. The presentation was recorded and available at <https://www.msssi.gob.es/profesionales/saludPublica/prevPromocion/promocion/desigualdadSalud/jornadaHaciaEquidadSalud.htm>

the 1980s (2003, 210). This long-standing and ubiquitous idea that living next to Gitanos is a source of problems is the core issue that leads to other representations of Gitanos and Roma. And it has a historical origin too.

Shantytowns and substandard housing was a mainstream phenomenon during the migration from rural areas to big cities that took place after the Spanish Civil War (1936-1939) (Castells 1983). Most of the neighbourhoods on the outskirts of Madrid, (specially in the south) were initially '*barrios de chabolas*' (shack settlements) where Gitanos and Spaniards from impoverished Spanish rural areas (San Román 2010) and poor people who lived in the centre but were ousted to the periphery settled down (Castells 1983). Castells claims that in 1956 twenty per cent of the population in Madrid lived in the outskirts' slums, which were illegal but tolerated (1983, 218). It was later, when the Francoist regime set forth a large-scale re-housing policy in the 1960s, that shantytowns gradually became an ethnic-related phenomenon (Río Ruiz 2009; quoted in Beluschi Fabeni, López López, and Piemontese 2014, 89). Most (but not all) Gitanos were excluded from these re-housing programmes due to the combination of the institutional racism of the Francoist regime and the difficulties of complying with all of the administrative requirements (San Román 2010).

In Madrid, after the decentralisation of the housing policies from the national to the regional government in the eighties, there were still 3,000 families living in slums and most of them were Gitanos (Nogués Sáez 2010). It was during those initial years of democracy that different institutional organisms were created with the purpose of "eradicating" shantytowns and relocating people either in apartments (the better-off), 'special typology neighbourhoods', or temporary camps (Aguilera 2016). The 'special typology neighbourhoods' were built purposefully to accommodate Gitanos' difference and they were the sole dwellers of these ghetto-like estates (Aguilera 2016; Gay y Blasco 2016). Beluschi Fabeni, López López and Piemontese, in their analysis of the linguistic construction of Gitanos in Spanish housing policies (2014), note that:

"the territorial segregation of Gitanos has taken place as a result of social stratification, rather than as a consequence of politically constructed and culturally based relation with the territory (such as the Nomadi in Italy). However, such segregation has been "culturalized" or "ethnified" at a later stage: in Spain the causes of urban segregation and bad housing conditions are explained, both in political and media debate, as a cultural phenomenon"(2014, 110).

Thus, the idea that shantytowns are a cultural phenomenon intimately connected with Gitano culture is predominant in Spanish society. Substandard housing, Gitano culture and ideas about progress intertwine to create a representation of Gitanos and Roma as people in need of “development programmes”. Gitanos (and Roma) are re-educable, but at the same time they are perceived as a “lost cause” because they continue living in informal settlements in marginal areas of the city. Gay y Blasco explains this association:

‘They were also described as massive eyesores in the modernizing capital, perched on the edges of Madrid, the first view of the city that tourists arriving by road or railway confronted. These shanty-towns had to be eradicated and their population had to be dealt with, brought into line with the rest of European Spain’ (2003, 208).

It is as if the rest of the Spaniards had embraced “European modernity” during the years of transition to democracy at the end of the 1970s and 1980s and Gitanos had remained unchanged with their old-fashioned culture. Similarly, the arrival of migrant Roma from Eastern Europe and their settlement on the outskirts of the cities in handmade shacks, in the very same areas that Gitanos have historically occupied, has reinvigorated the idea that nomadism –and self-isolation from Payos as well as living in precarious conditions– is something intrinsic to Roma and Gitano culture, and therefore, something that confirms that Roma and Gitanos are intrinsically the same but in different “developmental” stages.<sup>17</sup>

Substandard housing is intimately connected to Gitano culture in the shared social imaginary about Gitanos in Spain. Despite not all Gitanos living in informal settlements, the latter are perceived as something “Gitano” and to some extent the existence of settlements demonstrates the incorrigibility of some Gitanos who, despite the positive discrimination housing policies aimed at them, prefer to remain with their

---

<sup>17</sup> It is interesting to note that some anthropologists researching migrant Roma in Spain have challenged the culturalistic interpretation of their mobility patterns. For example, López Catalán (2012) argues that most of the migrants Roma with whom he conducted research managed to rent apartments (90% of migrant Roma in that context). This is possible because of the real estate market in that area, which enabled migrant populations to buy houses that they could then rent to migrant Roma. In this case Roma did not live in the stereotypical shantytowns. Lopez Catalan also suggests that migrant Roma mobility patterns were basically due to their precarious living conditions and their economic instability and not to any alleged cultural preference (López Catalán 2012).

unruliness in those undeveloped conditions. Throughout the ethnographic chapters I will develop on these ideas and how they intermingle with notions of citizenship and self-responsibility during the clinical encounters.

Finally, I would like to add that during my fieldwork, the ease with which the healthcare workers talked about Gitanos in pejorative terms surprised me. Interestingly, it was during the common sessions I organised in both primary healthcare centres that the healthcare workers were harsher in their comments compared with the private interviews. It seemed that nobody was afraid about the possibility of being accused of racism. For the healthcare personnel, it was completely legitimised to describe Gitanos as problematic, scroungers, childish and naughty, because it is taken for granted that Gitanos cause problems, misuse public recourses, do not take responsibility and do not follow advice.<sup>18</sup> Interestingly, during the interviews I conducted with the same healthcare workers, their opinions about Gitanos were much more nuanced and the tendency to generalise in pejorative terms tended to be contrasted with positive personal experiences with Gitanos.

Similarly, what I saw in the consulting rooms differed from the homogenised negative representation exposed publicly and I could observe an array of different practices when attending Gitanos and multiple ways of understanding cultural difference, and of identifying this difference and dealing with it. In the following chapters I analyse ethnographical material that illustrates the heterogeneous practices used when attending to Gitanos patients. Still, I found that there was a qualitative gap between what is said publicly, the way it is explained to the researcher in private and what is actually done in practice. My point is that, in my research context, what was expected was to talk about Gitanos in pejorative terms, obfuscating any public positive representation of Gitanos. Those positive representations, which I will show in the subsequent chapters, rest in the private realm but do not contribute to modify the negative stereotypes of Gitanos.

---

<sup>18</sup> It is true that there were other 'voices' during the sessions trying to challenge the mainstream ideas about Gitanos, but these voices did not manage to change the direction of the group and remained marginal within the global picture.

## 2. Spanish Public Healthcare

The Spanish Public Healthcare system (Sistema Nacional de Salud SNS) was conceived at the beginning of the eighties during the transitional years to democracy after the Franco dictatorship (from 1939 to 1975). After the 1978 Spanish Constitutional Act, in which the right to health protection for all Spaniards was recognised, the challenge for the new democratic government was to transform the existing system of social security (Bismarck model) into a national health service (Beveridge model) financed through general taxation and aiming to provide universal healthcare coverage (Garcia-Armesto et al, 2010). The SNS is a decentralised system: every regional government is in charge of the provision of healthcare services and the national government coordinates and guarantees the cohesion of this quasi-federal system<sup>19</sup>. Therefore, there are two levels of health policy: the national laws and decrees that establish healthcare coverage, benefit packages and pharmaceutical expenditure and the regional governments that organise the provision of services in their territories.

Public expenditure on healthcare is low in comparison to other European countries, and since 2010 it has progressively decrease from 6,8 % of the GDP to 5,6% in 2015 (Ortega and García 2015). This budget decrease has affected differently the different services that integrate the SNS; while hospital expenditure has been maintained during the crisis years, primary healthcare and public health have suffered the progressive reduction of their budgets. Although there are regional differences<sup>20</sup> the SNS budget is hospital-centred and therefore well suited for acute processes while it is worst suited to address chronic and complex processes, as public health and primary care are underfunded (Padilla 2016). Still, the SNS was doing fairly well in comparison to other European countries (Martin-Moreno et al. 2009) and for its public (Legido-Quigley et al. 2013). As previously exposed, budgetary cuts have not been homogeneously distributed and they have also affected universal coverage.

---

<sup>19</sup> Following the 1986 General Health Care Law, the SNS was organized as a combination of state administration and regional health services. Link to the law: [http://www.boe.es/diario\\_boe/txt.php?id=BOE-A-1986-10499](http://www.boe.es/diario_boe/txt.php?id=BOE-A-1986-10499)

<sup>20</sup> The regional government is in charge of organizing the healthcare services in its region, following the national regulation that establish the minimum services to be provided.



## 2.1 The National Scenario

At the national level, since 2000, access to healthcare was granted to all migrants registered in the local councils, regardless of their legal status. Before that date, irregular migrants were entitled on the same basis as nationals only if they were pregnant women or people under 18. Even though the Spanish immigration law (BOE 2000) guaranteed universal healthcare access, organisations such as Doctors of the World denounced the struggles irregular migrant went through in order to enjoy their right to healthcare (HUMA Network 2009). Administrative procedures and difficulties to register at local councils prevented those in most unfavourable conditions from accessing healthcare. In Spanish public debates on migration, the emphasis has been placed in portraying migrants as a drain on national resources, whether in healthcare or other social services, despite the data that show that migrants use health services less than the native population (Calderón-Larrañaga et al. 2011; Berra and Elorza-Ricart 2009; Soler-González et al. 2008).

However, in 2012, during the economic recession that prompted the implementation of austerity measures, the ministry of healthcare passed a decree law (BOE 2012) that redefined the public healthcare system. Under the pretext of ensuring sustainability and technological development, the decree law modified healthcare coverage from a resident based entitlement to an employment-status-based entitlement, reducing healthcare coverage to those who are considered insured<sup>21</sup>. This reduction in entitlements has been highly contested in public debates, not only in political arenas but also among healthcare professionals' organisations and migrant associations<sup>22</sup>. These groups have contested the law on the grounds of their duty to provide care – in

---

<sup>21</sup> The law introduces the new term 'insured', which mainly includes those who are working, retirees and people receiving unemployment benefits. The main criterion is that to be entitled you need to have contributed to the welfare system paying taxes through your work.

<sup>22</sup> There were different campaigns from different NGOs and professional associations, such as the Spanish Society of Family and Community Physicians. The most active at the national level is Yo Sí Sanidad Universal, born in response to the law. Some examples of the campaigns: <http://yosisanidaduniversal.net/portada.php> <http://www.derechoacurar.implicate.org/> <https://reder162012.org/>

the case of healthcare workers– or highlighting the flaws of the law<sup>23</sup>. Even though irregular migrants were not the only ones excluded from healthcare, they epitomised the public debate about the changes that the decree law introduced.

On the other hand, that same year the budget in health and social services was reduced by 13,65%, the areas most affected by these monetary restrictions were public health (a 45% cut to its budget) and professional training (75%) (Legido-Quigley et al. 2013). Moreover, due to the worsening of the working conditions, the precariousness of some sectors and the rise in unemployment from the beginning of the economic crisis, the strain on the healthcare system has increased, as these factors affect peoples' health. Similarly, the budgetary cuts in the funds to support elders and people with disability have indirectly shifted the support of elders and disabilities to the healthcare system (2013). There is some research that has already shown the effect of the economic recession in an increase of mental health problems (Gili et al. 2013; Malmusi et al. 2015), or the effect in mortality rates (Benmarhnia et al. 2014). The debate around the effects of the budgetary cuts in healthcare, the ideological bases that underpin them, and the available alternatives is still open in professional realms and, to some extent, in the public sphere (Cortès-Franch and González López-Valcárcel 2014). Nevertheless, it is important to note that in the last years, the number of people who have hired private insurance has increased notably to the extent that in 2016 around 25% of the Spanish population had hired a private health insurance (Simó 2017). A percentage of the private insurance rate (5%) belongs to the public workers that are able to choose between the SNS or private companies, but the increase has mainly been due to the hiring of new insurance policies by people who are already covered by the SNS, what healthcare analyst call the “double coverage”. The long waiting times to access some specialists as well as the saturation of public healthcare centres are pointed out as the reasons for this increase in private healthcare insurances (Simó 2015).

---

<sup>23</sup> For health economists, the main flaw of the law is that it mixes two different systems: on the one hand, the healthcare system is still funded through general taxation and thus, every consumer contributes to its funding while on the other hand, only those who pay taxes to the social security system (which does not fund healthcare system) are granted entitlements. For civil rights lawyers, the law violates the international human right treaties that Spain had subscribed, as well as it could potentially be against the 1978 Constitutional Act.

## 2.2 Madrid Public Healthcare: A Contested Scenario

At the regional level, Madrid healthcare has undergone a twofold process of openness to market strategies and neoliberal policies. Firstly, in 2009, the regional government shifted healthcare from a regional to a functional structure (which facilitated the introduction of private healthcare providers) while a law to regulate free choice of health professional was passed (BOCM 2009). Grounded on the principle of ‘patient’s freedom’ and advertised in every local media, the new law noiselessly shifted the responsibility from the regional government to provide quality healthcare, to the citizen who, from then on must be able to make ‘good’ choices to preserve her health. The emphasis on free choice tends to present healthcare as a commodity ready to be consumed, and this may contribute to modify the way citizens perceive not only healthcare but also the institutional role on its provision. If healthcare access is no longer a right but a product, governmental priorities move towards the creation of self-sufficient consumers able to attend to their own needs, not to provide quality healthcare. Professional roles are also affected by these changes, as healthcare workers’ mission is no longer to care for the population they attend to, but to provide services to those consumers who fulfil the requirements of an autonomous, self-caring patient.

The second change came in October 2012, when the regional government announced the privatisation of six hospitals and several primary healthcare centres in Madrid. This measure was highly contested and led to the creation of a social movement known as ‘*Marea Blanca*’ (white tide) where healthcare staff, patient associations and civil society defended the public health system. For more than one year, ‘*Marea Blanca*’ organised monthly demonstrations and took legal actions against the regional government for implementing a health policy that was not in their electoral programme. They did not only protest against the privatisation process, but also against the exclusion of irregular migrants from the national healthcare system. For this social movement, what was at stake was the defence of a healthcare system already endangered by the austerity policies and the fear of the destruction of the broader welfare system. That is why, as Janina Kehr (2014) argues, when the first case of person-to-person transmission of Ebola virus outside Africa appeared in Madrid in October 2014, the healthcare professional politicised the debate arguing that the Ebola case was due to the political negligence in maintaining the public healthcare

system. As Kehr further argues about the public debate on the Ebola case in Madrid, 'A sick state is on trial – a state whose governors reign for their own sake, a state who is sick from its economic policies' (2014). Therefore, the social defence of the public healthcare system was part of the broader social movement in defence of public institutions and against the implementation of austerity policies that the government was implementing.

Under this social and professional pressure, and with the regional court blocking the privatisation process, Madrid's government had to step back and renounce the privatisation of hospitals and primary healthcare centres. Although the '*Marea Blanca*' managed to stop the privatisation process, the healthcare services were not immune to the austerity measures and budget cuts. Primary healthcare in Madrid, which is considered the base of the healthcare system, has seen its budget reduced in a similar fashion to other services (public health basically) but with the difference that primary healthcare has been chronically underfunded (Simó and Gervas 2012). This decrease in funding has materialised in reductions of personnel – and the consequent work overload for healthcare staff – reductions in salaries, and the slimming of medical and nursing continuing professional development programmes. If the increase of migrant population highlighted old dysfunctionalities of the healthcare system related to healthcare personnel's performance (Vázquez et al. 2011), the austerity measures have intensified those dysfunctional patterns. The same professionals who protested against the privatization of the public healthcare system have to cope with the deterioration of the latter in their everyday practices.

The primary healthcare services in their actual form date from 1978, when the new specialist training programme on family and communitarian medicine started and the healthcare centre network was created (Epstein and i Carrió 2001). Differently from the NHS, the regional healthcare government area directly manages primary healthcare and it is the regional government who hires primary healthcare workers. Theoretically grounded on Engel's bio-psycho-social model (Borrell-Carrió, Suchman, and Epstein 2004) primary healthcare is the entrance door to the healthcare system: primary healthcare centres (*Centros de Salud*) are in charge of promoting health, carrying out preventive programmes and treating afflictions of the people living within the neighbourhood surrounding the healthcare centre. The healthcare personnel are nurses, general practitioners, administrative staff, social

workers and in some of the centres physiotherapists and dentists. In ideal conditions, nurses and general practitioners will tend to work as a team in adjacent offices, sharing the responsibility of caring for the health needs of the patients registered with them. Usually they share their impressions about patients and work together in the caring process. All the healthcare centre professionals are supposed to work as a team, with common the goal of contributing to the good health of the population they attend to. Regular meetings and training sessions are scheduled on a regular basis to discuss either future planning or clinical cases. Nevertheless, the different professional roles and the relationships between them play an important part in the way each member of the staff understands and justifies their work and position within the primary healthcare centre. The entanglement of the diverse professional identities with the institutional and organisational constraints shapes the different ways healthcare workers think about the population they attend to.

Regarding the professional roles, it is important to note the little importance given to relational aspects of the clinical work in medical schools in Spain. There are few universities that offer courses on patient-physician communication and even fewer that include medical anthropology or sociology in the undergraduate medical courses. Nurse undergraduate studies are more oriented towards a bio-psycho-social approach but still medical anthropology courses are seldom offered and there are always optional. Debates about the need of cultural competency in healthcare arise in the late nineties, when Spain became a migrant host country. Several national and regional plans aimed to include migrant population contemplated the need for training professionals in cultural diversity as well as social determinants of health (Vázquez et al. 2011). Similarly, in 2004 the ministry of health issued a special report on health and the Gitano community where they highlighted the importance of including cultural competence in healthcare professionals' training (MSC and FSG 2005). Besides, the National Roma integration strategy 2012-2020 underlines again the need to accommodate healthcare services to diverse population needs. However, non-substantial curricular changes have taken place and training is reduced to scarce elective continuing professional development courses. The budget reduction in professional training does not contribute to ameliorate the situation. The arbitrariness in the training in relational and cultural aspects of clinical practice is reflected in healthcare workers' concerns with the problems they find in the relationships with those considered culturally different (Seoane and Portero 2006).

Both of the primary healthcare centres where I conducted fieldwork were actively involved in the '*Marea Blanca*', but the success in the collective action was not directly translated to the workplace, where primary healthcare workers had to manage everyday work with less resources (both human and material) due to the continuous budget cuts. I followed most of the contestation process and the initial 'white tide' gatherings from London through mainstream media, social networks and conversations with close friends (who became close informants) so I built an idealised perception of the atmosphere I would find in the healthcare facilities upon my return to start my fieldwork. In my mind, and from the biased survey I did of the contestation events, I was expecting to find a lot of motivated and combatant colleagues who were proud of their ability to mobilise public society together to defend a basic right.<sup>24</sup> In my imagination, these colleagues were continuing their "fight" in the everyday practice at the healthcare facilities, trying to provide the best care possible. When I finally returned to Madrid and started my fieldwork, I found a quite different scenario, although it is true that the ashes of the contestation were still alive and it was the first topic to come up in conversation when I spoke to my former colleagues.

The first days at the healthcare centre, during the coffee break, most of the people were keen to tell me everything about the demonstrations, but this initial enthusiasm soon vanished and the usual complaints about the lack of resources, the packed agendas, the not-supposed-to-exist waiting lists,<sup>25</sup> the over-the-legal-limit ratio of patients/GP or patients/nurse, the annoying patients and their unmotivated consulting reasons... all effects of the chronic underfunding of primary healthcare and the budgetary cuts were expressed in these complaints, which overshadowed the enthusiasm of the 'white tide'. The increasing and overwhelming workload was

---

<sup>24</sup> The announcement that the regional government was not going to continue with the privatisation process came later during my fieldwork (three months after I started) so during the first months I shared the uncertainty that the healthcare workers were experiencing about their professional future. When the regional government announced that they were not going to pursue the privatization process, it was celebrated on social networks and in the media, but there were very few people (around 25 more or less) celebrating it outside the hospital.

<sup>25</sup> One of the principles that rules primary healthcare is accessibility: doctors and nurses have to be accessible without delay because primary healthcare is the open door to the healthcare system and, in ideal conditions, more than half of the health problems should be addressed or solved there.

burying the sense of capacity of the healthcare workers and their enthusiasm for the defence of the public healthcare system. The paradox of defending a public healthcare system –in general terms– while that same public healthcare system does not afford the necessary conditions to provide quality care, was the first thing that struck me when I came back to the healthcare centre. It was as if the defence of the public healthcare system did not apply to the everyday practices of that same system.

There are some interesting differences between the two clinics I was in that are related to the effect of the austerity policies, quite separate from the demographic specificities of the population they attend to. Both clinics faced a reduction in expenditure to contract locums during holiday periods and maternity or sick leaves. It is more and more difficult to successfully apply for the family-friendly measures to reduce their work hours, not to mention other kinds of permits. So the main burden of personnel holidays and permits falls on their colleagues. On top of this, almost half of the staff have temporary contracts, which are renewed every three months/one year on average, having lower salaries and facing more job uncertainty than those who have a permanent position. This situation was similar in both centres, although they cope with it differently.

The main difference between both centres is the number of people they attend to, which has been influenced by the 16/2012 decree law (the law that excludes irregular migrants from health care, as well as other people who do not satisfy the requirements) (BOE 2012). The healthcare clinic located in the city centre has seen a significant reduction of the population they attend to (more than 3000 people out of 17000; to give an idea of what it means for actual practice, the recommended rate is one physician per 1500 people, one paediatrician per 1200 children. So it means that their workload has actually been reduced). This decrease is partly due to the loss of entitlement to healthcare for irregular migrants. The neighbourhood is part of a larger district area, but it has its own identity as the most diverse neighbourhood in Madrid. Of its population of around 45000 people in 2012, 31% were foreigners from 88 different countries. Gitanos have been living in this neighbourhood for several years among working and middle class Spaniards, and traditionally working on antiques trade or activities related to Flamenco performances. The neighbourhood was not very popular despite its location in the city centre, but in recent years it has

gained more attention from real estate companies and investors and the house prices have increased significantly, ousting those who cannot afford to live there anymore.

The periphery healthcare centre has gone through the opposite process. Located in a new neighbourhood planned to host 28000 houses, its growth was suddenly stopped by the burst of the housing bubble in 2008. The original urban development plan has not been completely implemented, nevertheless from 2010 to 2012 the population increased in 10000 people. In 2012 there were 41851 people living in the area, most of them young couples with children. 13.1% were foreigners in the whole district, but most of them were living in the area where the settlement is located (with a foreigner rate of 45.05%). Moroccans are the largest group (around 27%) followed by Romanians (23%), Colombians (5%) Peruvians, Ecuadorians and Chileans (Dirección General de Atención Primaria 2014). Instead of seeing their workload reduced, it has steadily increased since the healthcare centre opened in 2007. In the original neighbourhood plan, three healthcare centres were planned, but only one has been built. So the rate patient/physician was around 2000 or even more. On top of that, they attend to part of the people who live in the informal settlement in collaboration with the healthcare van.

## **Concluding Remarks**

This chapter aims to provide a general background before delving into the ethnographic material. In the first section, I exposed the available data on Gitanos' health status found in biomedical literature and government-led research. I briefly analysed how Gitanos' representations as marginal or exotic population impinge the biomedical research conducted with Gitanos, both in the choice of research topic and in the kind of causal explanations used to discuss their findings. Interestingly, despite the scarcity and scattered character of the data, they are used and reproduced in different research articles and institutional reports without questioning the value of this data to account for a context other than where they were produced. The institutional research intended to provide better quality (or at least national-scale) information about the health status of Gitanos. Although the National Health Surveys have some methodological limitations that are important to bear in mind, they highlight the fact that the institutional integration or inclusion strategies aimed at



Gitanos are failing their purpose. One of the many factors involved in the lack of positive results of these strategies could be the reasonable anti-gypsyism that prevails in Spanish society, which is subordinated in the representation of Gitanos (and Roma as a new version of “old Gitanos”) as ‘individuals to be corrected’. The representation of Gitanos as mainly posing a conviviality issue because they do not follow the social norms is at the heart of the spatial segregation policies aimed at Gitanos and, as I will show in the following chapters, it shapes the everyday practices at the primary healthcare centres.

The second section of this chapter aimed to introduce the reader to the Spanish National Healthcare services through the exposition of the recent changes that have modified the grounds on which entitlement to healthcare is granted. Looking at the interplay of national and regional policies, I have shown how Madrid’s public healthcare system became a political contested scenario and how the ‘*Marea Blanca*’ movement epitomized the civil society movements against the government and its austerity measures. Nevertheless, the public mobilizations that managed to stop the privatization process, did not manage to reduce the impact of the budget cuts and chronic underfunding of primary healthcare. In the next section, a prologue to the ethnographic material, I illustrate this point with some pictures from the healthcare centres where I did my fieldwork.



## (Walls that talk)

Looking back at some of the pictures I took during my fieldwork, I found that the paradox of defending a dysfunctional public healthcare system was represented somehow through the posters at the healthcare facilities where I conducted fieldwork. The first thing that caught my eye were the numerous posters hanging on the walls making reference to the defence of the public healthcare system. At first glance, the posters of the opposition to the privatisation processes eclipsed the picture. However, a more detailed look at the other posters hanging on the walls, mostly next to or on the consulting room doors, shows the work overload of the healthcare workers.



Figure 2. Gynaecologist consulting room door.

Figure two shows the entrance door to the gynaecologist's consulting room; the colourful poster on the right of the picture is one of the typical posters used to advertise a house sale. It literally says "gynaecology and obstetrics for sale". These posters were used to highlight the fact that the regional government was selling a public good (the healthcare system) for the profit of private interest (the insurance companies). It also connects in a very subtle way the economic crisis and the bursting of the housing bubble as the causes

of the ongoing austerity measures with the privatisation of the public healthcare system. In doing this, both the economic recession and the privatisation processes are presented as being due to political negligence because politicians did not tackle the building bubble on time in order to decrease the effects of the economic recession on the welfare system.

Next to this flashy poster and under the consultation room number and doctor's name sign there is a piece of paper that provides information about the possible delay in the consultation time and warmly requests patients not to knock on the door but to wait until the nurse comes out and calls them. This kind of poster is not infrequent in the healthcare facilities and, even though the date is not stated on it, it could possibly have been there since before the budgetary cuts. Nevertheless, it signals something that is frequent and that most of the users of the healthcare system are already aware of – that there will be a delay in the consultation time.

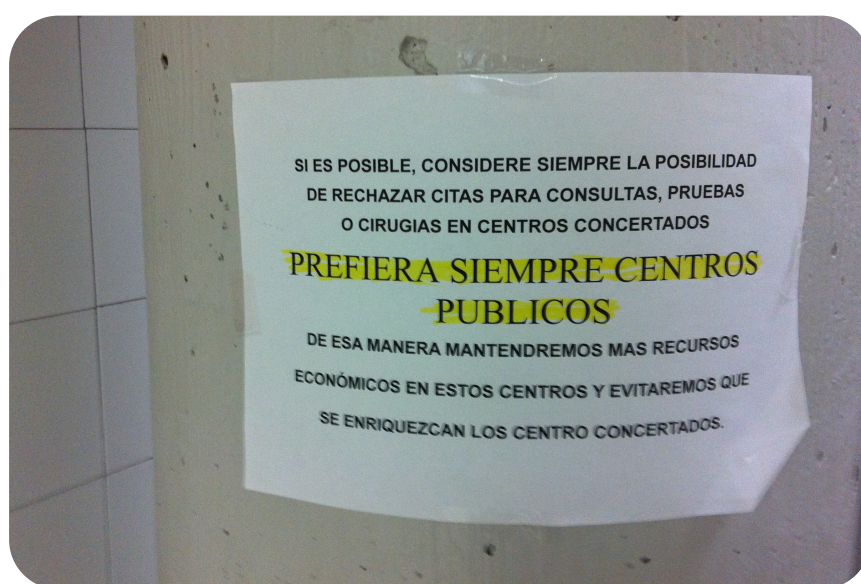


Figure 3. “Choose Public Healthcare” Poster

Another interesting poster is the one hanging on a column (fig.3), which could be seen everywhere at the healthcare centre. In that poster, which is anonymous, patients are encouraged to prefer public centres to private ones and consequently to avoid referrals to the latter<sup>26</sup>. Since the passing of the free choice of healthcare law in

---

<sup>26</sup> The message is ‘please consider, if possible, the possibility of rejecting appointments, diagnostic tests or surgeries provided in private centres subsidized by the regional healthcare system. ALWAYS

2009 (BOCM 2009), the planning of healthcare provision has shifted from a territorial to a functional base, easing the process of contracting private companies to provide public healthcare services. The groups that defend public healthcare denounced this change in the organisational structure of regional healthcare services as the first attempt to privatise the healthcare system. Both the “gynaecologist for sale” poster and the latter implicitly show that the personnel working in the consulting room support the ‘white tide’.



Figure 4. Paediatrician's consulting room door at the healthcare centre

Figure four is a picture of the door of a paediatrician's consulting room at the primary centre. In the middle of the picture we can see a childish style poster with the representation of a scene of two babies playing at being doctors. The message is similar to the one next to the gynaecologist's door: “please do not knock on the door,

we will call you when it is your turn, thank you”. This seems to be the central message, but what caught my attention is the number of warnings flourishing around the central poster. Looking carefully at the picture we can notice the traces of old adhesive tape, which means that some posters have been removed and new ones have appeared, giving us an idea that the door actually works as a communication device. However, the messages displayed and the places where they are can serve to help examine the way in which healthcare workers deal with the lack of resources.

The four different posters revolve around the same idea of making an adequate use of the healthcare facilities, and warn patients about the long waiting times if their appointment was not scheduled in advanced. One of the posters enunciates the reasons that do not justify an urgent appointment, such as prescriptions refills, bureaucratic procedures, health certificates and so on. The upper poster says ‘only health emergencies justify being attended without a previously scheduled appointment. If it is not the case, please always try to schedule appointments in advance so we can avoid the collapse of the services and unnecessary waiting times’. The poster hanging on the right side of the door insists on the idea of the ‘collapse of the service’ if patients do not use the public healthcare system in an adequate way and come to the healthcare centre without a scheduled appointment.

The fact that the door is used as a way to communicate with patients waiting outside indicates that usually patients have to spend more time than they would like in the waiting room. The content of the messages supports the fact that paediatricians have a larger workload than they can manage in the time provided. Nevertheless, most of the messages imply that patients are to blame, because their use of healthcare facilities is “abusive” as they do not follow the scheduled appointment system. Bearing in mind that primary healthcare is the entrance door to the healthcare system, its doors reflect the dysfunctionalities that this same system has and the constraints that healthcare workers face in their everyday practices and how they respond to them. These posters in the doors show the paradoxical healthcare workers’ stance of encouraging the use of public healthcare facilities over private ones while suggesting that the public healthcare services are saturated. It was in these spaces, in the waiting rooms and behind the doors at the consulting room, where the following ethnographic chapters are based.



## Chapter Two: The Admission Desk

‘The idea of bureaucracy amounts principally to a set of suppositions about categorization’

Michael Herzfeld. *The Social Production of Indifference*

‘It’s Monday early in the morning; I was at the healthcare centre on my way to the changing room when I bumped into Saray and her husband. They were sitting on the bench next to the entrance door. There was a long queue of people waiting at the admission desk; the queue stretched from the counter to the entrance door. The security guard was nearby; he was only hired for the weekend and half since Monday morning. When Saray saw me, she shouted, ‘Look! It’s la Bea!’ with her characteristic good humour. She walked over to me briskly and, looking at my startled, sleepy face, shook me, saying, ‘What is going on with you, Bea? Are you drunk?’ I replied something about her strength and the punch she just gave me while looking out of the corner of my eye at the security guard, who was following the whole scene with a puzzled expression. I asked Saray what she was doing at the healthcare centre and she told me that her mother-in-law got a phone call from the hospital telling her to come to her physician to see the results of an X-ray she had had the week before. I looked at the queue and saw Saray’s mother-in-law, Carmen, waiting for her turn; when she saw me, she exclaimed: ‘Look, it’s la Bea!’ and left the queue to come over to me. When she reached us I asked her what kind of X-ray she’d got, and she told me that it was a chest X-ray and that they told her to come urgently to the doctor to get the results; despite the fact that she already had an appointment scheduled for the following Friday, they told her to come on Monday. I was afraid they had found something pathological and serious on the X-ray, as they had moved up the appointment, so I told Carmen to go back to the queue while I

checked on why they called her to make an earlier appointment. So instead of going to the changing room I returned to the admission office and turned on the computer to look at Carmen's clinical records. When I found the X-ray, I focused on looking for signs of anything malignant: a lump in the lungs, something in the ribs... but there was nothing. I looked at the radiologist's report attached and it did not mention anything that justified changing the appointment. I thought I was looking at the wrong test, so I checked other tests: an abdominal ultrasound scheduled in two months, an old X-ray test... there was nothing else, so I closed her clinical records and went back to the queue to talk to her.

When I got back to the queue, Carmen was no longer there. Her daughter, Saray, was still sitting on the bench next to the entrance door with her husband, the security guy standing next to them. I asked Saray where her mother-in-law was and she grabbed my arm and brought me to the area of the waiting room where Carmen was waiting. When Carmen saw me, she stood up and came over. She stared at me and suddenly I felt self-conscious having this conversation surrounded by people who were looking at us. Trying to transmit closeness and serenity, I put my hand on Carmen's shoulder and told her that I had looked at the X-ray and that everything was fine, that there was no reason to be worried. With a happy tone of surprise, she said, 'Really? Everything fine?' And I assured her that everything was fine, adding that I did not understand why they had called her. Then she explained to me that it was not a phone call; she told me that when she did the X-ray, they told her that she had to go to her GP in three days to see if there was something like pneumonia or similar. With that extra information I understood where the misunderstanding was: it is routine after an X-ray to tell the patients that their GP can access the results in three days. It did not mean that they had to go in three days, but that was just the time it takes on average for the radiologist to check and write the report. Carmen understood that there was something wrong and so she had to go in early to find out with her GP.

Again, she asked me, as if wanting to be completely certain about it, whether everything was fine, and I nodded, so she added, 'Then I'm leaving. I am very, very busy because her husband (pointing at a woman who was next to her that I did not recognize) is in the intensive care unit at X hospital and we have to go now... so... it is not necessary to visit my GP today, is it? No point, right?' I repeated



‘No point’ and told her to go to the hospital if they were in a hurry; I would cancel the appointment. I told her to come to the previously scheduled appointment in three days. And they left, passing next to the security guy who was still standing near the door and following us with his puzzled gaze. I made a last joke with Saray about her strength and she replied, shouting, ‘What’s wrong with you, Bea? Are you drunk?’

The group of five people left the healthcare centre and I went back behind the admission counter. There, I went directly to the administrative clerk who had attended Carmen before. While I asked her to cancel the appointment, as it was all a misunderstanding, she looked at me in surprise and ironically responded, ‘Cancel the appointment? How come, if it was very urgent?’ The sarcasm was both in her tone and the way she was looking at me over her glasses. However, she was not directing any anger at me, just some sarcasm. As soon as I heard her say it was very urgent I started to explain, excusing Carmen for asking for an urgent appointment and her belief that there was a medical mandate for her not to wait. I kept on talking and talking until the clerk, still looking at me with a half-smile, said, ‘You do not need to give me an explanation; I noted down everything here, have a look,’ while pointing at the screen where Carmen’s appointment was registered. That information was followed by a long explanation, the same one I was giving her. After some joking remarks with the clerk I managed to leave the admission area, again passing in front of the security guy, who with a smile bade me good-bye’. (Extract from my fieldnotes. )

## **Introduction**

I decided to begin the chapter with this vignette because, even though it may seem anecdotal or banal, I think it highlights some important aspects that are intertwined in the way Gitanos access healthcare. In the interaction with the administrative staff – the ‘street level bureaucrats’ described by Lipsky (1980) – the framework that delimits who is included and who is excluded is put in practice. This framework shapes access to healthcare based on the situated “measuring” of deservingness, creating different kinds of citizens. Ultimately, the different degrees of legitimation or deservingness to access healthcare are moral judgements based, on the one hand, on the identification

of the patient as Gitano (and within this identification there are differences, too) and on the other hand, on Gitanos' representations in the collective social imagination.

In the vignette, some of the social representations of Gitanos are present in a nuanced way. For example, it is not coincidence that the security guy constantly appears in the vignette as an observer. His presence was contingent on his working hours, but he was alert because he identified Saray and her family as people who could generate conflict, although they were just sitting on the bench at the entrance. Gitanos, as I will outline later, are described as having the capacity to generate conflict. Saray and her family, having been identified as Gitanos by the security guy, were people to monitor. Coming to the healthcare centre in a group, speaking a little bit louder than other people, the kind of clothes worn or the smell of smoke in winter determines not only ethnic belonging but also belonging to the settlement.

I had not observed the interaction between the administrative clerk and Carmen because it took place while I was looking at the clinical records. Afterwards, when I talked to the clerk to cancel the appointment, she emphasised the fact that Carmen told her that it was “very urgent” when it was not. The clerk implied that Carmen had lied to her, or that somehow she had tried to fool her, which is one of the characteristics associated with Gitanos. Therefore, having identified Carmen as Gitana<sup>27</sup>, the plausible explanation was not a misunderstanding but a wilful lie. This interpretation was grounded on a set of stereotypes that depict Gitanos as duplicitous people who do not comply with the rules. Once identified as Gitana, your word is doubted.

Identification is fundamental in the process of considering healthcare deservingness. As I will show in this chapter, there are different ways healthcare workers identify Gitanos as such. In the previous vignette, both the security guy and the administrative clerk identified the patient as Gitana based on a set of stereotyped characteristics

---

<sup>27</sup> Unlike the security guy, in the case of the administrative clerk, who knows me and knows about my work, she identified Carmen as a shantytown dweller because Carmen and I knew each other, so she might be a patient from the settlement. Whether the administrative clerk identified Carmen as Gitana I do not know, but both labels (Gitana and shantytown dweller) are ultimately interchangeable as most of the healthcare workers identify shantytown dweller as Gitanos or Roma and Gitanos are mostly presumed to live in the shantytown.

through which they construct a meaningful whole of what being Gitana is. This mechanism of identification is what I call the stereotype working as a protocol, and it is frequently used to identify those Gitanos from the settlement or from a lower social stratum. A different mechanism of identification is what I call identification through acquaintance, where ethnicity only appears after getting to know the person better and it does not work as the lens that explains any behaviour of the patient identified as Gitano. I will examine these two mechanisms in depth in this chapter.

Finally, I would like to draw attention to the contradictory position of the administrative staff. They distribute scarce appointments with minimal information and they are accountable for doing “good triage”. But the administrative staff only have access to one part of the clinical records and therefore their decisions are based on what the patient says over the counter and the clerk’s interpretation. As I illustrate in the vignette, the first thing I did when Carmen told me about the X-ray was to consult her clinical records in order to understand what was going on and give her appropriate counselling. If I were not able to access the X-ray results I would not have been able to give her any advice. That is why the administrative clerk can only trust what the patient is telling her and act accordingly. However, GPs and nurses do not always acknowledge these limitations and occasionally they show their discontent and reproach the administrative staff for not performing their task properly. These institutional hierarchies as well as the social dynamics in the different healthcare centres and the workload they face impinge on the way appointments are negotiated, decisions are legitimized and the way that different interpretations of the rules are understood.

## **1. Configurations and Representations**

### **1.1 *Tipos De Ciudadanos* (Types Of Citizens): Who Is Who?**

Administrative staff can be considered “street level bureaucrats” inasmuch as they are representatives of the state and their everyday practices give ‘concrete shape and form to what would otherwise be an abstraction’ (Gupta 1995, 378; quoted in Auyero 2012)

The administrative staff negotiate entitlements to medical care and grant access to primary healthcare in their relational practices. Policies that are in place, institutional norms and the interpretation made of them mould administrative staff practices. Some researchers have shown how the state is constructed in the everyday practices and representations of ordinary people (Gupta 2005; Joseph and Nugent 1994) and the importance of those small procedures, dull paperwork and unexciting routines of bureaucrats in the processes of granting access to basic citizen's rights.

Michael Lipsky, in his classic book 'Street-Level Bureaucracy: Dilemmas of the Individual in Public Service' (1980), explores the ambivalence public workers face in their everyday practices. He defines 'street-level bureaucrats' as 'public service workers who interact directly with citizens in the course of their jobs, and who have substantial discretion in the execution of their work' (1980, 3). Lipsky analyses the main facets of street-level bureaucrats in different institutions that are analytically similar. He highlights how street level bureaucrats have a double function, both to allocate and to redistribute resources following the state's policies, and how they do so in an immediate and personalized manner (1980, 8).

The whole of healthcare workers at the primary healthcare centre fall into the street-level bureaucrat category; however, the administrative staff has a peculiarity that differentiates them from the "clinical staff"<sup>28</sup>: they can grant or deny access to healthcare, as they decide who is entitled to healthcare and who is not, and the conditions in which access can be granted. One of the roles of the administrative staff is to be a gatekeeper of the healthcare system. As Lipsky puts it, 'They hold the key to a dimension of citizenship' (1980, 8). Following the policies in place and institutional norms, the administrative staff create frameworks of inclusion and exclusion. However, these norms and policies simply work as a template to be interpreted in every specific case. The frameworks of inclusion and exclusion are reinterpreted in

---

<sup>28</sup> The status of administrative staff is complicated, as they are not considered "full" healthcare workers. The main difference is that whereas physicians and nurses have to abide by their deontological professional code, administrative staff does not follow that regulation. Despite having to comply with the obligations of secrecy and respect for the privacy of healthcare users, they are not obliged to provide care. Therefore, granting access to healthcare is not regulated by the ethical duty to provide care but by the bureaucratic policies in place at the moment.

every specific case and moulded to the personal and concrete circumstances in which the encounter takes place; in Lipsky's words, 'the reality of the work of street-level bureaucrats could hardly be farther from the bureaucratic ideal of impersonal detachment in decision making' (1980, 6). In clinical settings, some authors have already shown how despite legal frameworks granting universal healthcare coverage, there were intangible obstacles to accessing healthcare (Larchanché 2012; Castañeda 2012; Fassin 2009). In her research into the French healthcare system, Stephanie Larchanché(2012) found that irregular migrants were not accessing healthcare despite having the right to do so because they were represented as illegitimate population groups; therefore irregular migrants encountered obstacles which thwarted their access to healthcare.

As previously explained in chapter one, during the time I was conducting fieldwork, a set of measures reducing universal healthcare coverage were introduced in the Madrid public healthcare services. The right to access healthcare was denied to those migrants in irregular situations (mainly not having a residence permit and thus not being able to apply for a social security number) or who did not comply with all the requirements for attaining "insured" status. The decree-law that regulated the new healthcare coverage was a national law and the different regions had to create the normative framework to implement it. The 16/2012 decree-law (BOE 2012) not only restricted universal access to healthcare but also modified the funded prescription system, with patients paying a percentage of the cost of their medicines, based on their income. In Madrid, as a result of the implementation of the decree-law, the primary healthcare administrative staff received a new set of norms to assess who was complying with the new requisites to access healthcare and who was excluded.

Administrative staff are used to facing frequent changes in regulations regarding access to healthcare. In the last decade, they have seen how the requirements to get a healthcare card<sup>29</sup> have significantly increased. For example, when I moved to Madrid

---

<sup>29</sup> The healthcare card is the document that proves entitlement to healthcare. It is a plastic card, similar to a credit card, where you can read the user's name and affiliation number, as well as the expiration date. Each regional healthcare system has a different model and they differ in the design but mostly feature the same characteristics. Madrid's healthcare card does not feature the picture of the cardholder.

(that was twelve years ago) and needed to get a healthcare card, I did not need proof of address; they just asked me for my address and my social security number. Twelve years later, proof of address was a necessary requisite. However not just any proof of address was valid: what was required was proof of municipal registration (*empadronamiento*) of no more than three months validity.

As the requisites to obtain a healthcare card increased, a new set of documents granting “exceptional” access to healthcare appeared. These documents were issued on paper, never as a card, and their validity was usually restricted to less than one year. As access to healthcare stopped being considered a universal right, the regional government established a system to legitimate some people to access the healthcare system without fulfilling the standard requisites. Quotas were distributed for obtaining access due to exceptional circumstances and hierarchically organized in what I call “the hierarchy of legitimacy”.

## **1.2 The Hierarchy of Legitimacy**

Exceptional legitimacy to access healthcare selectively was granted on the basis of the following criteria: time or clinical conditions. Time was a criterion in two different ways: when determining a health emergency and when determining who was considered a minor. Age determines access as long as the patient falls into the category of being a minor (under 18 years old). In those cases, access is granted to protect childhood because the Spanish state signed and ratified the Convention on the Rights of the Child in 1989 (BOE 1990). In the convention, article 24 declares:

‘States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services’ (BOE 1990, art. 24)

Before the enforcement of the new requirements children were not asked for proof of address to obtain the healthcare card. After the implementation they could not get the plastic card, just a paper granting the access that corresponded to the new healthcare citizen’s category: “*menor titular extranjero*”. “*Menor titular extranjero*” literally means

‘foreign minor title-holder’, which in this context means that the state directly entitles the child, instead of obtaining those entitlements through her family.<sup>30</sup>

On the grounds of the same convention on children’s rights, pregnant women have access to healthcare during pregnancy as it is the state’s duty ‘to ensure appropriate pre-natal and post-natal health care for mothers’(BOE 1990, art. 23). This assumption is not as straightforward as the previous one but the reasoning is that women are considered the carriers of a child-to-be (the foetus) who should receive the best care possible. Pregnant women are granted access not on the grounds of their own reproductive health but to protect the foetus.

The second situation where healthcare is provided without having the standard healthcare card is in case of a health emergency. A health emergency is considered to involve those conditions that if not treated immediately, can lead to the death of the person or severe injury. Therefore, in those situations, the law regulates that everybody, regardless of their entitlements to healthcare, be able to access emergency services. However, disincentives to going to emergency rooms were placed at the hospital’s admission desks. One example of these disincentives was the routine procedure of giving a “payment commitment letter” at the hospital emergency admission desk to those patients who did not have a healthcare card with them. Before being admitted to the clinical area, the patient needed to sign this document, agreeing to pay for the care provided if the healthcare card was not presented in three days<sup>31</sup>. Despite the law granting universal access to emergency rooms, institutional norms were jeopardizing this right, as people who did not have a healthcare card refrained from going to the emergency room out of fear they would have to pay.

The other criterion that grants selective access to healthcare is having a medical condition: not every medical condition grants access to healthcare, only certain

---

<sup>30</sup> In this context, Children usually get access to healthcare through their parents’ entitlements, in a category that is called *beneficiario* (benefiting from). For children whose parents do not comply with the requirements and therefore they themselves cannot benefit from their parents’ entitlements, the state provides entitlements directly to the child until she is eighteen years old. When reaching the age of majority, access to healthcare is denied if the requisites are not fulfilled.

<sup>31</sup> Similarly, pregnant women are given a commitment-to-pay document when they go to the hospital to give birth without a valid healthcare card.

selected conditions serve as a key to obtaining healthcare. Granting access to healthcare on the grounds of chronic diseases is the category that has gone through the most changes in recent years, and disappeared completely after the decree-law 16/2012 (BOE 2012) went into effect. The criteria used to select which conditions grant access to healthcare mostly follow two kinds of logic: the logic of humanitarianism and compassion and the logic of control and defence. First, the logic of humanitarianism, as I have already mentioned in the introduction, is not about recognizing rights but creating exceptions based on pity and compassion. The logic of control has to do with the threat that some infectious diseases can pose to the whole of society and not only to the individual. Therefore, in the name of public health, both exceptional measures<sup>32</sup> and exceptional rights may be granted.

Thus, “the hierarchy of legitimacy” goes as follows: if you are a legitimate citizen and fulfil all the administrative requisites you are a bearer of full rights and therefore you can obtain a healthcare card, which fully entitles you to use the healthcare system. You are at the top of the hierarchy of legitimacy. Perhaps you do not fulfil all the requirements to obtain a healthcare card but you are eligible to obtain an exceptional-access healthcare document. You are second in the hierarchy; you may have access to most of the healthcare services but with more difficulties than if you had a healthcare card. Finally, if you can neither apply for a healthcare card and are not eligible for an exceptional-access document then you are at the bottom of the hierarchy of legitimacy and only if you have an emergency health problem will you be granted access to healthcare.

The administrative staff have to navigate all these categories and the continuous changes they go through. In this shifting context with not always clear premises, while sometimes even having to enforce contradictory mandates (such as facilitating universal access to the emergency room while giving a “commitment to pay” document), the administrative staff have their own ways to make sense of, interpret and implement “selective access to healthcare”. In the pre-established template of the different types of citizens, each administrative clerk has to locate the patient that she has in front of her in the corresponding category of citizenship. But these categories

---

<sup>32</sup> In chapter five I explain the exceptionality of public health measures in greater depth.



are neither fixed nor universal, and the interpretation and enforcement of the different laws and regulations vary, depending not only on the administrative worker but also on the person who is trying to access healthcare.

The role that administrative discretion and these amorphous and changing regulations have in the exclusion of people from healthcare has already been revealed in the case of immigrants in Spain (Calavita 2005; Sàez Sellarès and López Catalán 2009 specifically about migrant Roma). This research highlights the administrative hurdles and institutionalized irregularity constructed by law in the process of accessing healthcare. Calavita signals the personal character that the decision to facilitate access takes:

‘These practices of course depend on the good will of the local district officials and clinic staff who use their considerable discretion to override the logistical hurdles to registration- hurdles which others just as unilaterally, and presumably with just as much deliberation, pile up’ (Calavita 2005, 109).

On their hand, Merixell Sàez Sellarès and Oscar López Catalán also signal variability in the practices of the administrative staff and the difficulties migrant Roma face in order to access healthcare:

‘these difficulties are frequently insurmountable when related to access to healthcare. Moreover, our own experience during fieldwork reinforces the idea that in some cases, without our accompaniment it would have been very difficult or sometimes even impossible to access certain services or procedures’ (Sàez Sellarès and López Catalán 2009, 162).

The variability in the practices at the admission desk was also a constant during my fieldwork. For some people, especially those living in the informal settlement, access to healthcare was frequently curtailed because they did not comply with the necessary requirements to obtain a healthcare card. Still, some administrative clerks interpret the legislation in a stricter sense than others, depending on the specific patient and, as I will show later, on who accompanies the patient. In what follows I analyse how these interpretations of the norms are articulated in relation to different notions of citizenship.

### 1.3 The Spaces of Citizenship

The description of the administrative staff's work directly reflects Lipsky's description of street level bureaucrats' work, as he puts it :

‘They determine the eligibility of citizens for government benefits and sanctions. They oversee the treatment (the service) citizens receive in those programs. Thus, in a sense street-level bureaucrats implicitly mediate aspects of the constitutional relationship of citizens to the state’(1980, 8).

It is clear therefore that administrative staff have a role as representatives of the state in as much as their valuations are crucial for putting a basic civil right, such as access to healthcare, into practice; a right that, ultimately, depends not only on a legal framework but also on the interpretation of that framework, which is influenced by institutional mandates as well as by personal views and social representations. In practice, rights take on multiple shapes, possibly as many as there are different ways of interpreting the law. In a way, administrative staff members are not only representatives of the state but are also representatives of the collective social imagination of the context they live in. This is why looking at the relational aspect of citizenship is relevant in this context, as it can help unravel the ‘intangible obstacles’ (Larchanché 2012) that lead to unequal access to healthcare. Jeannette Pols coined the term “relational citizenship” (Pols 2006), which I find useful to analyse the practices at the admission desk. Arguing that most of the theories about citizenship are focused on the individual, Pols coins relational citizenship ‘to draw attention to the social and material relationships through which people negotiate their differences and establish relationships in which these differences are accommodated’ (2016, 178). By talking about relational citizenship we can draw attention not only to the normative framework that defines individual civil rights but how these rights are contingent on the relational practices that make them effective. Citizenship is, thus, a matter of socialization.

In a similar fashion –highlighting the relational aspects of citizenship- Sabine Ootes (Ootes 2012) investigates the spatial metaphors used in mental health policies to talk about citizenship. She argues that most of the talk about citizenship has to do with drawing the borders of the civic domain and therefore defining who falls inside this civic domain and who falls outside it. In consequence, Ootes defines citizenship as ‘being-in-place’. There are two kinds of spaces evoked when talking about

citizenship: that which corresponds with a traditional, Euclidean vision of space, and that which refers to the space of interaction or social networks (Ootes et al. 2013, 14) In my research context, these spatial tropes linked to citizenship were used to represent Gitanos as “outside of society”. Inasmuch Gitanos are portrayed as not ‘being in place’, their legitimacy as citizens –and therefore their right to access healthcare – is called into question. In what follows, I investigate how these spatial tropes are used at the admission desk.

### **Islands of non-citizenship**

The construction of Gitanos as outsiders in the social imagination has to do with the two main spatial realms that Ootes et al. (2013) describe: Euclidean space and the social network space. As previously developed in chapter one, substandard housing, settlement dwelling and Gitanos are connected in the collective social imagination in Spain. Gitanos are believed to be the main dwellers of the different settlements on the outskirts of Madrid. The representation of Gitanos living in these areas at the edges of mainstream society is also associated with informal –and sometimes illegal - activities, such as scrap-metal collecting (or drug dealing). In these representations of Gitanos, territorial exclusion is due both to their informal activities and their own choice to be outside, glossing over the historical and institutional processes of Gitano’s segregation.

However, living in these settlements, which are islands of non-citizenship, precludes Gitanos from accessing basic services such as healthcare. The main limitation in the case of healthcare is the difficulty to get registered at the municipal office as a resident of the settlement, which is called *empadronamiento*. The *empadronamiento* is the municipal registry as a resident in a district; everybody, even homeless people, should be able to register as a resident in the place where they spend most of their time<sup>33</sup>. However, it is difficult to prove that you live in a place that is not legally recognized, as is the case of informal settlements. When settlement dwellers apply for *empadronamiento*, a police officer needs to go to the settlement within no more than two weeks to verify that that person lives there. If the applicant is not at her house when the police officer goes to check, then the application is denied. A procedure that for someone living in the

---

<sup>33</sup> For example, in the case of homeless people, they can get an “*empadronamiento*” at the bench where they sleep.

adjacent neighbourhood takes just one visit to the municipal office, for settlement dwellers involves waiting up to two weeks for the police officer's visit.

So, in territorial terms, living in the settlement is being not-in-place, and therefore not a citizen able to fully exercise one's rights. The use of the Euclidean space's trope to delimit the borders of citizenship is the norm at the primary healthcare centre that attends to the settlement dwellers. For example, at the primary healthcare centre, the commission in charge of the slum's health matters is called "Comision de Poblacion Excluida" (Socially-Excluded Population Council) and the settlement population is referred to as a "socially-excluded population". In a way, healthcare staff tend to identify everybody who does not have a healthcare card as a settlement dweller. In this case, the territorial metaphor also works as a category to delimit the borders of citizenship. Furthermore, it is rare to find an article in the press about the settlement that does not make reference to the proximity and isolation of the slum<sup>34</sup>, as if it were an "anomaly" to have that island of non-citizenship so close to the city centre<sup>35</sup>. The reference to the physical space, which is both close and isolated, is a constant.

Accordingly, one way for settlement dwellers to become citizens is to be relocated, or as Ootes et al. put it, 'In this logic becoming a citizen depends on changing xyz coordinates, because these coordinates attest that citizens are living independently' (2013, 13). Being relocated means being able to get a valid proof of address (*empadronamiento*), which is a guarantee of access to healthcare and other fundamental rights (schooling, for example). To some extent, relocation also serves to shed the stigma of being a settlement dweller, someone with no rights.

---

<sup>34</sup> The characteristic opening of the articles is 'Only twelve kilometers from the Puerta del Sol (city centre, country centre'...); examples are:

[http://ccaa.elpais.com/ccaa/2013/04/25/madrid/1366882412\\_355279.html](http://ccaa.elpais.com/ccaa/2013/04/25/madrid/1366882412_355279.html)

<http://www.elmundo.es/sociedad/2016/04/01/56fd5e80ca4741914b8b4672.html>

[http://www.eldiario.es/desalambre/integracion/exclusion-gallinero-chabolismo-madrid\\_0\\_158534207.html](http://www.eldiario.es/desalambre/integracion/exclusion-gallinero-chabolismo-madrid_0_158534207.html)

<sup>35</sup> Interesting to note that other tropes are used here to represent the settlement, as it is depicted as a place of backwardness (not following the progress of the rest of society) and "elsewhere", not rich and European Spain, the place of the 'other'.

Still, Euclidean space is not the only metaphor used to refer to the rights of the settlement dwellers. Being socially excluded is not only about living in the settlement; it also has to do with not being part of the social network, not having adequate relationships with people who are not excluded. Ootes et al. describe it as follows:

‘The idea of citizens as part of social networks implies a notion of space, which, like Euclidean space, makes use of an inside/outside logic. With few social contacts, one is exterior to the civic domain. But in this case, the civic domain is conceived in terms of social network connectivity rather than Euclidean coordinates’(2013, 14)

This metaphor of citizenship as networked space is directly related to the representation of Gitanos in the eyes of mainstream society. It stresses the idea that Gitanos are endogamous, that they do not want to relate to people who are not Gitano, constructing them as a group of people who “do not want to integrate” or who exclude themselves from mainstream society. From this premise –their unwillingness to relate to other people, their belonging to a social network that does not grant citizenship- the ‘explanatory model’ (Kleinman 1978) of Gitano difference is articulated, mostly based on stereotypes, as well as on the main discourse regarding Gitanos. Projects of citizenship -or social inclusion as they are called for Roma and Gitanos- in large part depend on disciplining Roma and Gitanos to converge with the prevailing norms of citizenship (Foucault 1979, 2003a). Therefore, the relational space trope is not exclusive to the Roma and Gitanos from the settlement; it is also used to refer to Gitanos who live in regular neighbourhoods, inasmuch their social network is conceived as isolated from the civic domain.

An interesting example of how this logic of citizenship as social network works is the accompaniment system or “*acompañamientos*”. When someone has difficulties gaining access to healthcare, different associations have volunteers to accompany the person and mediate with the street-level bureaucrat in charge. As Sàez Sellarès and López Catalán (2009) note in their research, the arbitrariness at the admission desk made their presence necessary for their Roma patients to obtain what they claimed for. These accompaniments are not exclusive to Roma or Gitanos; there are different kinds with different purposes. The most active group during my fieldwork was “*Yo sí sanidad universal*”, which literally means “I am pro universal healthcare”: they are a group of healthcare workers and civil society who contested the law that reduced

healthcare coverage. Their target group was migrant people who did not have a residence permit and therefore, from one day to the next, lost their right to healthcare (July 2012). *Yo sí sanidad universal* advocated for universal healthcare not only by accompanying people; they also conducted informative talks with the staff of primary healthcare centres, presenting the legal possibilities for granting access to undocumented migrants and possible legal loopholes<sup>36</sup>.

In their demand for universal healthcare coverage, another interesting strategy that *Yo sí sanidad universal* used was to give out badges and stickers that people placed on their white lab coats and computers. During my fieldwork, in both healthcare centres the staff wore these badges; it was a way to identify themselves among their colleagues and make their stance clear. At first glance, I had a snapshot of the different professional standpoints coexisting in the two healthcare centres through the simple observation of the coats and the badges on them. But the badges were not only helpful to orientate the anthropologist; their main function was to guide those patients without a healthcare card and those seeking access to healthcare. Thus, the badges became a system of identification for connecting with the right person to grant you access to healthcare (or at least to try to find a way to do so).



Figure 5. One of the badges of the 'pro-universal healthcare' movement

---

<sup>36</sup> *Yo sí sanidad universal* also created a file of cases and a registry of healthcare professionals who declared themselves conscientious objectors to the law. I explore the healthcare workers' contestation to the law and the legal loopholes they resort to guarantee access to healthcare to migrant women somewhere else (Aragón Martín 2017)

The accompaniment system, not exclusive to *Yo sí sanidad universal*, works through mediation: a citizen with full rights (recognizable as such) accompanies a citizen-to-be and demands the degree of legitimization to use the healthcare service that the applicant can attain. Sometimes this citizen is part of an inclusion program for refugees or migrants because organizations working with migrants and refugees are aware of the “intangible obstacles” to accessing healthcare. As with volunteers from universal healthcare advocacy groups, their presence at the admission desk helps to legitimate the applicant’s request. For the applicant herself, already having a relationship with a network that supports her in her demand for rights (the right to healthcare in this case) is the first step to becoming a full-fledged citizen with all the rights, the first step to ‘being-in-place’.

### **Identification and Public Space**

Looking back at the opening vignette, Carmen did not face the difficulties previously described in order to access healthcare; she did not have to struggle with the documents because she already had her healthcare card. Actually, Carmen has a chronic condition and she usually goes to her physician instead of seeking care at the van. Only in exceptional situations –or as a product of random chance, like in the vignette- does Carmen see the van’s workers. Carmen and I made our acquaintance some years ago, when her daughter-in-law (Saray) had a premature baby that we followed up with at the van. Carmen and Saray live together in one of the most isolated areas of the settlement: the road to get to their house (the whole family lives together on a small plot of land) is not paved and the closest bus stop is some kilometres away (and buses seldom stop). So, for them, coming to the healthcare centre (or other places) has an added difficulty: they need to have a car or get a ride from someone. When they travel in their car it is not infrequent that they take advantage of the trip for other purposes, and give a lift to other people who need to go into the neighbourhood.

That is one of the reasons why sometimes the people from the settlement come to the healthcare centre in groups. In the vignette, Saray and her husband were sitting on the bench at the entrance, just waiting for Carmen, because after Carmen’s consultation they had to go to the hospital to visit someone else. They were not

accompanying Carmen because of an intrinsic “Gitano” cultural trait<sup>37</sup>; it was just a matter of logistics. Nonetheless, the presence of the group in the public areas of the healthcare centre raised some alarms; the security guard did not take his eyes off them. He only went back behind the admission desk after Carmen and her family left the healthcare centre. Coming to this healthcare centre as a group helps to profile people as coming from the settlement or being Gitanos or Roma. And this identification prompts a series of measures such as being alert to potential conflict.

Let’s now pay some attention to where this identification takes place: it is at the entrance to the healthcare centre, in a public space where everybody can see what is going on. The presence of the security guard beside the couple reinforces the idea of “unrest” attributed to settlement dwellers. People in the waiting queue and those in the waiting room can see the scene, and for some of them, the security guard’s attitude confirms their suspicions; for others, the scene would raise these suspicions. Being in the public space of the waiting room just widens the scope where Gitanos are identified as such and treated as troublesome. Being in a public space while displaying private information is one of the characteristics of the admission desk and waiting rooms. The interaction between the administrative staff and patients is visible to anyone around; sometimes the conversation is even audible for those in the queue who are close to the counter. The next extract of my field journal shows another interaction at the admission desk that I found useful in researching the interplay between the public and the private and the bargaining of legitimacy to access healthcare.

## **2. Practices (Encounters)**

### **2.1 (Re)moving Legitimacy**

‘At the admission desk there are three people behind the counter dealing with the public and there is another desk in the back for the

---

<sup>37</sup> On the cultural explanations of difference that I expound on somewhere else, fatalism explains the difference in access to preventive measures and the accompaniment of the extended family to the doctor because they fear bad news.



orderly. The orderly is in charge of helping out in the laboratory room early in the morning when the blood tests are scheduled. I used to benefit from his absence by sitting at his place and having a discreet look at what was going on at the counter. The clinic opens at eight a.m. and usually in the first hours there is a queue of people waiting to make appointments. It is an open space and the three people working behind the counter are quite close to each other so you can hear almost everything. Despite the fact that information provided by patients should be confidential, at the counter it is difficult to maintain privacy, and even more difficult at busy moments such as the early morning

I was sitting at the back desk looking something up on the computer and I saw a patient I knew from the settlement waiting in the queue. When it was her turn she asked for an urgent appointment with her physician. The clerk told her that there were no free slots for the day and asked the patient why it was urgent. The patient explained that she had been to the emergency room in the hospital the night before with an asthma crisis and that she needed the treatment and the prescription. When the administrative aid heard 'prescription' she quickly replied in a mechanical fashion: 'We cannot make urgent appointments to get prescriptions, it is forbidden, and even if I give you the appointment, your doctor will not give you the prescription'. The patient insisted that the treatment was very expensive and that she could not buy it without the doctor's prescription<sup>38</sup>. The clerk replied in the same distant and mechanical way, 'There is nothing I can do; filling prescriptions is not a reason to get an urgent appointment'. The father of the patient, who had been standing next to her quietly, intervened, asking the clerk what he should do, if his daughter could not see her physician she could not get the treatment. Then she would get worse and would need to go back to the emergency room. He added that the treatment was really expensive, more than 100 euros and he did not have that money to pay.

The clerk, showing more understanding but with the same tone of resignation said that there was nothing she could do, because there

---

<sup>38</sup> The official prescription carries a discount on the full price of the medicine; usually it is 40% but for chronic conditions such as asthma or diabetes, the discount is larger. Medicines are available over the counter with the emergency room report but in that case, the patient has to pay the full price.

were no appointment slots free for the day and the physicia was not going to write the prescription anyway. Then, the clerk suggested that they could go to the pharmacy and ask the pharmacist to give them the treatment without paying in advance. The father, getting more and more angry and raising his voice, but still in a polite way told her: ‘So you are telling me that there is nothing you can do and you think that at the pharmacy they are going to lend me that money just for free?’ The clerk was getting nervous and trying to end the conversation; she told the father to go to a pharmacy where they know him and added that she was very sorry but there were nothing she could do.

At that point the people in the queue were looking at the scene, because even though it was not aggressive, it was quite loud and was taking quite long, so the queue was getting longer and the scene was attracting more and more attention. I had the feeling that the conversation was getting nowhere and that the patients were not going to leave until they solved the problem that brought them to the clinic, so I approached the clerk and asked her if she needed any help. She explained the situation and the problem with the appointment and the prescription to me and while she was talking the patient recognized me. ‘Ah, you are the one who used to come to our place.’ I nodded and asked her how she was doing. The father, who hadn’t met me before, said, ‘Look, miss, I really do not have the money to pay for the treatment. I already went to the pharmacy and when they told me how much it was, I could not believe it. I am asking for an urgent appointment because she really needs the treatment. If she doesn’t use the inhaling system she is going to get worse’. I told him that I understood and that he was right, that his daughter needed the treatment, but I needed to find a way not to make the administrative assistant feel I was interfering in her decision while at the same time getting the prescriptions for the patient.

So I asked when the next available appointment was (in two days) and asked them if they could come that day for the follow-up. Meanwhile, they could wait in the clinic until the nurse and physician from the van arrived and they could write the prescriptions for her. The patient and her father agreed and the clerk agreed too. And then I moved back to the back desk. When the nurse working in the van arrived, I told him about the issue with the prescription and he wrote the prescriptions and gave her part of the treatment. He encouraged her to visit her physician in two days

to see if the treatment was effective and to maybe schedule some other tests in order to adjust the treatment and prevent her from having a new asthma crisis.

After the patient had gone, I talked with the clerk, excusing myself for sticking my nose into her job and for being so intrusive. I explained to her that I had heard the father getting more and more angry and I wanted to avoid a confrontation. She told me that it was ok, that she was grateful I had come to help her and that she did not know what to do because she could not give urgent appointments for prescriptions. She told me that nevertheless the father was exaggerating with the price of the treatment and that it was surely not so expensive, but anyway she was happy the problem did not go any further because of my intervention. I discussed the case with the nurse from the van, and he was not surprised about the incident and questioned the purpose of his job: 'You see, we are supposed to be a bridge between the settlement and the clinic, and when we succeed in bringing people into the clinic, they do not accept them. There is no room for them in the clinic'.

(Extract from my fieldnotes)

This extract from my fieldnotes is representative of the kind of interactions that take place at the admission desk to get appointments when they are a scarce resource. Moreover, this extract shows how the deficiencies of the healthcare system are shifted towards the patient's responsibility. The patient needed a physician's prescription, something that she was entitled to. If the physician who helped the patient in the emergency room had written a prescription for her, there would be no problem. However, doctors working in emergency departments do not write prescriptions because they are cautious about the '*pull effect*'<sup>39</sup> it could trigger, and by not providing the official prescription, they try to keep people from just going to the emergency room when they run out of pills. The rationale is not to make it so easy so as to encourage people to come.

---

<sup>39</sup>The so-called pull effect is an expression frequently used in my research context. It refers to the unproven phenomenon whereby undocumented migrants and other disenfranchised groups communicate with others in similar situations to encourage them to take advantage of social services to which they are not entitled.

Although the patient did everything she was told, she did not manage to get her prescription until I intervened. She came to the healthcare centre, waited her turn in the queue and asked politely for an appointment. If there were free appointments for the day, there would be no problem but, as the GP had a full schedule, only legitimate reasons for urgent appointments were considered. Even though the patient followed the established procedure to get her treatment, the administrative clerk considered that her request was not legitimate. The case signals the pitfalls and dysfunctions of the healthcare system: duplication of procedures, saturated timetables... in sum, patients travelling through the healthcare landscape without getting adequate care. But interestingly in this case, the patient was to blame because she asked for an urgent appointment for an inappropriate reason (a prescription refill).

There was a disagreement between what the patient was told to do and what the administrative clerk considered was right. The key element of this disagreement was putting together a prescription and an urgent appointment. One of the main premises at primary healthcare centres is that writing prescriptions is not a legitimate reason to be given an appointment for the same day. Patients must learn that they have to plan in advance when they are going to run out of medicines and schedule an appointment beforehand. In the eyes of healthcare workers, scheduled appointments are a fundamental requisite for the healthcare system to run smoothly, and everybody should contribute to teaching patients along these lines. Some healthcare workers would argue that there are situations when this premise is not applicable, as it would mean neglecting the patient or poor care (as could be in the case above). However, the interpretation and adherence to the rules depends on the considerable discretion of the administrative clerk who manages the case.

In the case of the asthma patient, not only was the urgency of the appointment not acceptable, but the attitude and explanation that the patient's father provided was unacceptable too. Actually, for the administrative clerk the father was "exaggerating" the price of the treatment with a duplicitous objective. At that point, the clerk did not consider that not getting the treatment would make the patient feel worse and go back to the hospital. Instead, she was focusing on the possibility that the father may have been lying to her, trying to deceive her by exaggerating the price of the treatment.

In the opening vignette, the administrative clerk had a similar reaction when I told her to cancel the appointment: by expressing disbelief in a sarcastic tone, the clerk was manifesting that she already knew that Carmen's demand for an urgent appointment was not appropriate. This certainty, that Roma and Gitanos demand urgent appointments that are not motivated by a legitimate reason, is common sense among the administrative staff (and to some extent among doctors and nurses, too). Non-legitimate urgent appointments pertain to the set of stereotypes that represent Roma and Gitanos as misusers of the healthcare system, therefore making them suspicious and illegitimate patients.

The clerk took for granted that Carmen was scheduling an urgent appointment that was unnecessary, and that was the reason why she wrote down all the information in the physician's record. Writing down Carmen's story was the way the clerk had to demonstrate to the physician that there was nothing she could do to avoid the "wrong" appointment. As the clerk was accountable for scheduling the appointment, she justified herself by shifting the responsibility to the patient. This need for justification signals two things: first, it denotes the common-sense representation of Roma and Gitanos and second, it shows the degree of pressure that physicians and nurses apply on administrative staff to stop people from making appointments. This kind of pressure and the interactions it creates at different healthcare centres is very different depending on the healthcare centre's workload and on the professional herself (and the interpersonal relationship with the administrative staff, as well).

But why were both administrative clerks so sure about the "wrongness" of the appointment they had scheduled? Why did they emphasize the idea that Carmen and the other patient were expressing that it was very urgent? The story that Carmen told the administrative clerk was plausible and not uncommon. There was no reason to suspect that it was not so and that Carmen was cheating. Nor was there reason to think that the patient's father was lying about the treatment's price in the second case. Moreover, Carmen was visibly worried and nervous about learning the X-ray results, which was completely understandable if the misunderstanding is taken into account. However, the administrative clerk emphasized the urgency with which Carmen asked for an appointment.

## Being on Time

Most of the administrative staff I interviewed shared the idea that Gitanos do not make good use of the healthcare system. When asked to elaborate, they explain that Gitanos misuse it in two ways: it is a misuse of time and quality (not at the right time and not for the right reasons). Strikingly, all the administrative staff mentioned these premises in the interviews, with no difference between the two centres or among administrative staff with different roles. To paint a simple picture, even the administrative staff who supported universal healthcare coverage shared the representation of Gitanos as misusers. Despite this homogeneity in the administrative staff's discourse, their practices were much more heterogeneous and nuanced. As previously explored in chapter one, administrative staff shares the 'reasonable anti-gypsyism' (Van Baar 2014) that prevails in the Spanish context.

Some illustrative quotes from the interviews with administrative clerks:

'Well, what is true is that they (Gitanos) use the healthcare system differently from the rest of us... mmmm... first, because they have not interiorized the idea of scheduling appointments, having pre-established norms... they do not have that'<sup>40</sup>

'Couldn't you choose another population group? I have a fixation with them... we do not have that many (Gitanos) here... but we see them a lot!! You come from the outskirts of the city so this is not new to you (knowing what Gitanos are like)... but here we have been educating them for twenty-five years! Still, they do whatever they want' <sup>41</sup>

'What I think is... well, this happens with non-Gitanos, too (urgent appointments)... I mean, it is the immediacy, I mean, they (Gitanos) want to

---

<sup>40</sup> lo que pasa es que bien es cierto que ellos utilizan la sanidad pública de una manera diferente a como la utilizamos los demás, eh... lo primero pues ellos no tienen el concepto como tal de cita previa, de unas normas preestablecidas... no las tienen

<sup>41</sup> 'no podías haber escogido a otra población? Es que les tengo una manía... nosotros no tenemos muchos, pero cunden mucho. Hombre! Si vienes de el barrio x ya sabes de lo que te estoy hablando, pero es que a los nuestros les llevamos educando 25 años... y siguen haciendo lo que les da la gana'

visit the doctor and downstairs (at the admission desk) they don't stop until they force an appointment'<sup>42</sup>

“[Gitanos] are not used to it, well I believe it is because of ... because of the cultural issue”<sup>43</sup>.

Other research has already pointed out the association of Gitano patients with inappropriate urgent appointments. Sàez Sellarès and López Catalán (2009) describe how administrative clerks sometimes take for granted that Roma want an urgent appointment without asking. Similarly, Ayala (2008) shows the clash between the Gitanos settlement's dwellers' and the healthcare system's understanding of time. Even so, the analysis of the logic that underpins this connection has not been undertaken yet. The connection between immediacy and Gitanos is based on the assumption that Gitanos are not citizens with full rights; despite their entitlements (in case they have them), they do not have an adequate relationship with the healthcare system and therefore they are in this case not “out of place” (as Sabine Ootes would say) but “out of time”. The logic goes as follows: Gitano patients may have a healthcare card, which grants them access to care, but they have to mould themselves to the regulations of the healthcare system. As Gitanos do not follow the rules, they should not have access to healthcare.

However, healthcare workers acknowledge that requesting urgent appointments is not specific to Gitano patients, and they admit that the number of urgent appointments also depends on the availability of empty slots to schedule a regular appointment. When the first available appointment means waiting four or five days, the number of urgent appointments increases, as patients consider that it is not an acceptable delay. During my fieldwork I observed that in the periods when the workload increased and urgent appointments were more frequent, the healthcare staff tended to blame both the patients and the planners for their packed daily schedules. Healthcare workers tended to understand the urgency of some appointments just because the delay was not acceptable. Regardless, healthcare workers expressed their concerns and

---

<sup>42</sup> yo lo que creo, vamos que también pasa en los payos.. los horarios, o sea es la inmediatez, o sea, ellos quieren ser vistos y abajo hasta que no fuerzan la cita no paran

<sup>43</sup> no está acostumbrada, pues yo creo que es por su ... por su tema cultural

annoyance at having such a workload to cope with<sup>44</sup>. Partly, they judged that some of the patient's reasons for seeking care were not acceptable, an argument that pertains to the debate about the medicalization of life and the role of primary healthcare workers. This is an ongoing debate in the Spanish healthcare arena, and although I am not going to pursue the analysis of this debate, it is important to mention it as it also influences the question of cultural difference in healthcare settings.

In this context of difficult working conditions due to budget cuts, personnel shortages and blaming third parties down the line for the dysfunctionalities of the system (physicians and nurses blame both administrative clerks, planners and patients; administrative staff blames patients, planners and physicians and so on....), the Gitanos's use of healthcare is still explained in terms of cultural difference. Even though Gitanos request the same thing as other patients (healthcare without delay), administrative staff interpret Gitanos' requests as qualitatively different. And this difference signals the status of Gitanos as not being citizens with full rights.

The next quote from one of the group sessions helps to illustrate this difference:

‘Admin: Yeah, but things are different, because for them (Gitanos) it is always urgent, I mean... they say... no, but I have been two....mmmm, I started coughing... I am coughing...

Physician: they are very exaggerated!!!!

Admin: They are very exaggerated with symptoms, the general population (non-Gitanos) wants to be attended to without delay because they do not have the time, they have to work... I know it is not the way, but it is their right... they, the Gitanos they just exaggerate their symptoms, mostly it is that, mmmm ok, they have their motivations and that means... but... it is completely beyond them (referring to getting used to scheduling appointments)<sup>45</sup>

---

<sup>44</sup> This argument is further developed in the section Healthcare as a Contested Scenario, where I analyze the different warning notes hanging on the walls and consulting room doors.

<sup>45</sup> Sí, pero porque las cosas son distintas, porque para ellos siempre es urgente, es decir, es que llevo dos ummmmm, he empezado tosiendo... estoy tosiendo

GP: son de exagerados



In this fragment the logic that underpins Roma difference is made explicit. Whereas the reasons non-Gitanos patients have for requesting an urgent appointment are perceived as legitimate (working, time-management reasons) and therefore the administrative staff concludes, '*It is their right*'; Roma patients' requests are based on illegitimate reasons (*'exaggerating symptoms'*). Yet, being able to visit a primary healthcare physician without delay –called accessibility in public health literature- is one of the characteristics of primary healthcare and a right for those who are entitled to healthcare, regardless of the patient's motivations or the manner the patient uses to request it. This right is clear for non-Gitano patients but is curtailed for Gitanos because their motivations are judged as illegitimate. Gitanos are suspicious of lying, exaggerating their symptoms just for their own benefit, and this suspicion demonstrates how they are perceived as illegitimate.

### **Real/Fake appointments: stereotypes working as a protocol**

Both in Carmen's and the asthmatic patient's cases, the way the administrative clerks made sense of what happened was that the patients were exaggerating (about the treatment price, about the seriousness of the results) with the only purpose of obtaining an appointment that, following the clerk's reasoning, they were not entitled to. The stereotype of Gitanos as duplicitous people<sup>46</sup> permeates the professional realm of the administrative staff, producing the following self-fulfilling prophecy: Gitanos are mendacious and I can prove it because they lie to obtain "illegitimate" appointments.

In fact, the administrative staff use the idiom of fake versus real appointments to differentiate between those appointments that are considered legitimate and those

---

Admin: muy exagerados con el síntoma, la población general quiere que se les vea en el día porque no tienen tiempo es decir, es que no es la manera porque tengo derecho porque es... ellos los gitanos es una exageración de síntomas, sobre todo, emm en sus motivaciones eso significa pero claro.... no les entra en la cabeza

<sup>46</sup> About the stereotype of Roma as tricksters, just recall the controversy about the definition of Gitano in the Real Academia de la Lengua (RAE) dictionary. The last entry for Gitano is *Trapacero* (trickster). Roma advocate groups asked the RAE to remove that entry and the RAE director replied that it was not their function to be politically correct but to describe the real use of the language. This argument would be valid if the RAE dictionary were a descriptive dictionary, but it is a prescriptive dictionary, so to some extent the RAE dictionary states that Gitanos are tricksters.

that are not. The idiom of fake appointments signals moral judgements regarding the health-related deservingness of Gitano patients. Heide Castañeda (2012, 830) defines health-related deservingness as ‘ “migrants”’ shifting and historically produced experiences of socio-political exclusion from their countries of residence, often leading them to be portrayed as unwanted, undesirable, and unworthy of services’. Beyond entitlements, the social stigmatization of migrant populations – applicable to Roma and Gitanos in this case- as illegitimate hinders their right to access healthcare, since they are perceived as undeserving populations (Fassin 2005a; Larchanché 2012).

In defining Gitanos’ appointments as fake, the administrative staff dispossesses Gitano patients from the right to access healthcare on the same grounds as non-Gitano people. As long as Gitanos are identified as such, suspicion is raised about their intentions. Progressive familiarity with Gitano patients and involvement in administrative tasks helps to decrease mutual mistrust between Gitano patients and administrative staff. For those patients who are identified as Gitanos, they have to prove that they deserve the benefit of the doubt. If not, stereotypes about Gitanos structure the way they are perceived and the provision of care. Similarly to the function of a protocol, the stereotype organizes the steps to be followed. Protocols are frequently used tools in healthcare practices. Algorithms, protocols, decision-making trees... that is the everyday reality in primary healthcare centres: there is a protocol at the admission desk for the chronic conditions prescription system, an algorithm for heart attack management, an emergency home visit algorithm... in sum, healthcare workers are used to these tools to make decisions in their everyday practice. At the admission desk, the template with the different types of citizens, in which entitlements are granted, is another kind of protocol. Marc Berg states that ‘All of these tools, however, have in common that they are or can be read as a set of instructions telling medical personnel to do A in situation B’ (Berg 1997, 1081). At a time when standardized practices and evidenced-based medicine are praised as models of good practice and good care, reasoning through protocols is mainstream in clinical settings. Protocols have the potential to both explicate and regulate professional work (Löwy 1995). It is because of this double potential of protocols that I argue that the identification of Gitanos through stereotypes works as a protocol. Paradoxically, while protocols and tools alike are conceived to standardize practices (to avoid personal bias) in the case of the use of stereotypes as a protocol to identify Gitanos, the protocolized reasoning serves to standardize the prejudice and naturalize it.

In both ethnographic vignettes, patients used the correct channels to access healthcare; they followed the instructions provided by healthcare workers and went to the healthcare centre. However, they were portrayed as duplicitous and illegitimate patients. Protocolled identification represents Gitanos in a way that obfuscates other possible interpretations of their motivations, other than the organized stereotypes as protocol. It does not matter that both patients could be described as “good users” of the healthcare system, according to their experiences. Neither does it matter that despite their difficulties to access public services from the settlement they managed to arrive at the clinic. Still, the stereotype prevails and permeates throughout the clerk’s interactions. As the nurse from the van said, ‘When we succeed in bringing people into the clinic, they do not accept them. There is no room for them in the clinic’. This statement by the van’s nurse summarizes the main, previously explained ideas: the representation of Gitanos as outsiders ultimately curtails their rights as citizens, specifically their right to access healthcare. There is no place for Gitanos at the healthcare centre because their place is the settlement, the island of non-citizenship.

In both cases the use of stereotypes as a protocol is clear: It works as a template with boxes to tick when an attribute is present: coming to the clinic in a group, talking in a special way, asking for an urgent appointment... When a clerk ticks most of the boxes, the patient is identified as Roma or Gitano and from then on the relationship will be guided by stereotypes about Gitanos and their cultural difference.

The protocol is explanatory; it provides the necessary explanations to understand the patient’s motivations and needs. But stereotypes as protocol are not only an explanatory mechanism; they also regulate the way care is provided. In the ethnographic cases presented, protocolled identification triggers an explanation about the patient’s motivations that differentiates Roma and Gitanos from the rest of the population and represents them as misusers. Similarly, protocolled identification regulates administrative practices, as these practices are shaped by the explanations the stereotypes as protocol provide. In both ethnographic cases, the patients managed to resolve their problem, but in the case of the asthmatic patient, it was not until I intervened that the conflict was solved. The administrative clerk interpreted that the patient’s father was lying and there was no option for the patient to see a physician and get her prescription. Would the administrative procedure have been different if the father’s explanation was not taken as mendacious? In Carmen’s case, the

administrative clerk wrote down the patient's demand just to justify her action of scheduling an urgent appointment without the "adequate" justification. Would she have written down the explanation if she believed what Carmen was saying?

It is worth analysing the context in which the vignettes take place: in both cases there was difficulty in scheduling an urgent appointment and obstacles to exercising the right to visit a general practitioner without long delays. The administrative clerks had to deal with the conflict between the scarce resources available and the patient's needs and demands. In both vignettes the use of stereotypes as a protocol takes place in a context of scarcity of appointments, where the clerk has to find a justification for her decision. As previously explained, the administrative staff need to make decisions about who gets an appointment and who does not with very little information.

Despite their lack of clinical training, administrative staff are in charge of deciding if a delay in care is possible or not. Unsurprisingly, both healthcare centres had a protocol to decide whether it was an urgent appointment or not. Although the protocols differed a little from one centre to the other, both of them clearly stated that any kind of administrative procedure (prescriptions, sick leave, clinical records...) were by no means to be considered urgent. Similarly, there was a protocol to define whether a physician or nurse should attend to a wound and similar things. In sum, the scarcer the appointments and the greater the workload and the amount of rules, the more the protocols and algorithms to decide how to allocate appointments at the admission desk increase. If physicians' and nurses' schedules were not full and the next available appointment was not in five days, urgent appointment protocols and similar tools would not have that much importance.

When there are few resources (in this case physicians and nurses), the administrative staff continuously have to evaluate the patients' needs with the tools they have available. The saturation of healthcare centres has a double impact on administrative work: first, it alters the quality of the work as the administrative staff are in charge of making decisions that do not correspond to them. Secondly, their role as gatekeepers is intensified to deny access instead of facilitating access to healthcare<sup>47</sup>. In a context

---

<sup>47</sup> One example of how denying access to healthcare is put into practice is the 'commitment to pay' letter mentioned previously in this chapter. These letters are not useful from a financial point of view,

where patients are perceived as enemies and primary healthcare is considered not the entrance to the healthcare system but the trench to halt an overwhelming workload, the administrative staff are in the front line and the ones who have to contend with the conflict between patients' (citizens') expectations and limited resources. My argument is that even though scarcity and the deterioration of working conditions are not the only reason, they contribute to the reinforcement of stereotypes and their use as a protocol (and therefore the standardization and naturalization of these stereotypes). Following Huub van Baar's idea of 'reasonable anti-gypsyism' (2014) as a prevailing representation in my research context, administrative staff (and other healthcare staff alike) participates in the reproduction of this trope. However, this "acceptable" prejudice does not interfere with their practice directly until they have to distribute scarce resources and assess the legitimacy of the patient's claims, be it health-related deservingness to obtain a healthcare card or an appointment with a physician or nurse.

In this section I have analysed the different factors that intervene in the identification of Roma and Gitanos as such and how the use of these stereotypes as a protocol defines the relationship with the administrative staff. The use of stereotypes working as a protocol has standardized and to some extent systematized prejudice against Roma and Gitanos, giving shape to what Huub van Baar (2014) calls reasonable anti-gypsyism. Ultimately, the use of stereotypes working as a protocol constructs Gitanos as illegitimate patients and curtails their access to healthcare. This illegitimacy is based on ideas revolving around the concept of time and the alleged discrepancy between the Roma's use of time and the healthcare system. These kinds of practices, in which the stereotypes work as a protocol, were not rare at both admission desks. Still, during my fieldwork I observed other kind of practices that I analyse in next section.

---

as it is difficult to get the money afterwards. However, patients are not aware of these difficulties and the letter serves as a disincentive to using the healthcare system.

## 2.2 Beyond The Protocol: Making The Acquaintance Of Gitanos

‘We have a family that always comes, we know their names, their surnames... and as soon as they come it is always urgent, urgent... and it is always urgent’<sup>48</sup>. (Administrative clerk)

As I previously mentioned, almost all the administrative staff that I interviewed shared the negative representations of Roma and Gitanos as misusers of the healthcare services and, to some extent, as duplicitous patients and scroungers. In contrast to this, the actual practices I observed at the admission desks during fieldwork were not as negative and homogeneous. Sometimes, the negative representations were the determining factor in the way access to healthcare was granted -as the case when stereotypes work as a protocol- but there were other practices less influenced by these negative representations. This kind of practices in which the stereotype does not cloud the administrative clerk’s perception of the Roma patient is what I call identification through acquaintance. In what follows, I am going to analyse some ethnographic examples that are representative of these practices. If the quality of the working conditions and saturation of the clinic were influential in using stereotypes as a protocol, in the case of practices based on familiarity with Gitanos, the different ways the administrative staff position themselves within the different understandings of their professional role are crucial. This is not to say that structural factors are not important –and of course these factors have an influence on the choice of the professional role inhabited in different practices- but they are placed in a secondary position.

One of the shared ideas about Gitanos in both healthcare centres was that Gitanos choose one trusted person to interact with, both at the admission desk and in medical consultations. Those ‘reference professionals’ are aware of their role as references for Gitanos, but in practice they are not the only ones attending them, despite this idea of being the “clerk for the gitanos”. One of the ‘reference clerks’ put it in this way:

‘At the administrative area something similar happens; I do not know why they choose one person, and they take that person as a reference and we are

---

<sup>48</sup> ‘Tenemos una familia que viene siempre, sabemos nombres, apellidos, y según entran a urgencias, urgencias, urgencias, siempre es urgencias’

back to the same thing that happens with physicians... they always look for ... in this case I am the one that always, sure, you heard my colleagues saying, “All the Gitanos want you.” I do not treat them in a special way, but I do not know why they want me, because I treat them the same way, I do not care if they are Gitanos or...’<sup>49</sup>

This clerk is making her position clear: it is not because she gives favoured treatment to Gitanos that they choose her; ultimately she does not know why they choose her. Nevertheless she thinks that it must be something about Gitanos and not a choice derived from her specific way of treating them. For this administrative clerk it is important to highlight that fairness is a principle that guides her professional practice: she treats everybody in a similar fashion. However, it seems that Gitanos choose her when they go to the admission desk. There are two important factors that help to understand why this ‘reference clerk’ figure occurs. Firstly, it is not that the ‘reference clerk’ treats Gitanos with positive discrimination; but we have to look at how these clerks’ practices differ from other practices at the admission desk. Secondly, looking at the history of Gitanos and their relationship with institutions reveals the established mutual distrust and the need to find trusted professionals (instead of trusted institutions).

The administrative staff are continuously confronted with the dilemma of social justice -how to facilitate equitable access to care- and distributive justice –how to distribute a scarce resource with fairness. Different ways of understanding what social justice means and different understandings of their role as either caregivers or just as administrative assistants shapes the practices of the different clerks at the admission desk.

It is interesting to note that administrative staff are considered a part of healthcare personnel but their status diverges from physicians’ and nurses’ inasmuch as they do

---

<sup>49</sup> ‘En el área administrativo les pasa igual, no sé por qué cogen a una persona que la cogen de referencia y volvemos a lo mismo que los médicos... siempre quieren, en este caso soy yo que siempre. Habrás oído a mis compañeros decir ‘es que todos los gitanos quieren contigo’ yo no les hago nada especial, pero no sé por qué conmigo, porque yo trato igual, a mi me da igual que sea gitano que’

not have to abide by the same deontological code. Administrative staff have to follow the guidelines of the personal data protection law but they do not go further than that. While physicians and nurses are obliged to provide care in any circumstance, not just during their working hours, the administrative staff's tasks are limited to the working time and space. However, their work is crucial for healthcare to be provided, as they implement the frameworks of inclusion/exclusion or distributive justice.

There are different ways the administrative staff make sense of their professional role: these different understandings are not represented by specific clerks having a fixed role and thus we can talk about representatives of ideal types, in Weber's sense (see for example Burger 1976). My argument is that there is a shared collective imagination where all the different meanings ascribed to the professional role are present and available to justify specific practices in a given context. Administrative staff uses those different meanings depending on the specific situation they are managing or confronting. The main ideas regarding the administrative staff's role revolve around the two main points that define their realm of work: the ideas of social and distributive justice.

### **Social justice and the boundaries of administrative staff's role**

I will start with an extract from my field notes to illustrate this point.

'I returned to the healthcare centre and interviewed Juana, the administrative clerk, who tells me that she is the reference for the Gitanos at the healthcare centre. I recorded the interview but in the end I stopped the recording and lost the final comments. She recalls how once there was an episode of a two-year-old toddler (she referred to him by his name) who was brought to the healthcare centre "dead" and the paediatricians resuscitated him. She tells me that there was a huge commotion, as is expected in these cases, but this time it was even bigger because the whole family was there. The clerk tells me that she accompanied the child's mother during the event because the mother was very nervous and now, every time they come to the admission desk, they only want her, the "blonde" as they call her, to attend them. She adds that she does not mind them calling her blonde, because she also speaks frankly to them about the things she does not like, as when they changed the surname of the children (the father stopped recognising them as his progeny) just to get more social benefits. She told them that in her



view that was not right, that they should not do that. And she tells them straightforwardly. But she also helps them when they need it because as she says, she knows their personal stories and their problems. She talks about a couple: the husband is/was a drug user and the wife phones the healthcare centre every time her husband has an appointment with the physician to check if he is really there and to ask whether he has finished yet so she can go and look for him to keep him from the temptation of using drugs. That is not a regular practice at any primary healthcare centre (it may be even irregular in legal terms!), but for her, the administrative clerk, it is important because she knows their story and she feels she has to help them. She does not care about the personal data protection law because for her what is important for that family is that the husband stays away from using drugs. Juana has great appreciation for her job; she knows she is good at it and she feels that doing a good job is important both for the patient's health and for the healthcare centre to run well. I really enjoyed talking to her; actually I did not feel she was dodging the issue at any time. She is usually smiling and transmits confidence in what she says.

I like that another administrative clerks call her the oracle...'

In this extract from my field diary I noted the comments that Juana made after I turned off the recorder. These off-the-record comments illustrate what she wanted to share outside of the 'official' record of the interview. And interestingly, what appears when the recorder is off is what she may consider the most personal take on her job. The story of the emergency with the toddler or the relationship with the worried wife shows how Juana expands the limits of her role as an administrative clerk to handle the contextual needs of the patients. But in order to recognize the patient's needs in the toddler's case, empathy was needed whereas in the second case, some kind of acquaintance with the patient was necessary. Juana's attitude in these two cases was not influenced by the fact that the patients were Gitanos, as she would highlight. She inhabits a role with mouldable boundaries and these boundaries are defined after a close examination of the patient's need.

Unlike when stereotypes work as protocols, in this case the patient's need is not established by preconceived ideas about Gitanos. For example, when Juana talks about the commotion at the healthcare centre when they brought the almost dead toddler, she emphasizes the fact that the commotion was bigger than in similar

situations because “*the whole family was there*”. The stereotype about Gitanos coming in big groups to the healthcare centre (and likely to generate conflict) surfaces in this comment. Nonetheless, this stereotype was not guiding Juana’s response: instead of calling the security guard, she approached the toddler’s mother to accompany her at that difficult moment. Similarly, instead of judging the patient’s drug use and associating it with being Gitano, Juana supports the patient’s wife and reassures her when she phones the healthcare centre. In this case, this kind of care is only possible because Juana knows the family’s story, because she had gained certain acquaintance with them. Besides, the wife knows that she can call Juana to ask her about her husband. This is what can be characterized as approachability<sup>50</sup>. Approachability goes beyond the material aspects of access and includes the intangible relational aspects of healthcare.

In both examples, the role that Juana inhabits is not the one that limits administrative tasks to organizing appointments, following the established rules and checking requirements to grant healthcare cards. The role of the administrative clerk represented in these examples is not purely administrative in that strict sense; it has the characteristics of a caregiver role. In both cases, the clerk’s motivation is the patient’s needs and the clerk tries to handle those needs with the resources available. That could mean sitting next to a suffering mother to try to comfort her or asking for a phone call to reassure the caregiver of a chronic patient. There is not a protocol that establishes these responses in similar situations, and therefore this kind of attitudes tends to be taken not as strictly “professional” but as a kind of necessary willingness to do a good job. As one administrative clerk puts it:

“And well, we... well, here we do not ... ok, it is also true that to work in a healthcare centre like this one, either you have certain qualities... that we are not better or worse than other people, I mean I do not say this because I think we are ... but you need to know how to handle the population”  
(Administrative clerk, March 2014)

---

<sup>50</sup> The concept of approachability as used here was developed by the Working Group in Medical Diversity at the Max Planck Institute for the Study of Religious and Ethnic Diversity in which I participated. Other members of the group that participated in the approachability project were Kristine Krause, Michi Knecht and David Parkin.

Quantifiable tasks -those that can be measured and assessed, such as scheduling appointments and making healthcare cards- are considered the core of the administrative job. However, the performance of those tasks is radically altered by the “*certain qualities*” that make administrative staff “*know how to handle the population*”. Moreover, those qualities speak to the notion of social justice and equality. Within the spectrum of understandings of their role, some understand their administrative clerk’s role as simply performing mere administrative tasks. In this understanding, the idea of social justice is based on a notion of equality in the provision of standardized, similar treatment to any patient. Therefore, a good practice would be that which is standardized, predictable and replicable in other patients. It is thus measurable and assessable. A different understanding is that of the administrative clerk’s role as caregiver, the notion of social justice is underpinned by an idea of equality that prioritizes adjusting the provision of services to the patient’s needs. In this logic, a good practice would be the one that best handles the patient’s needs with the resources available. The emphasis is not on the protocolized tasks but on answering the demands of the patient, moulding the answer to her specificities. Still, the division between administrative duties and “extra” duties at the admission desk remains and the inclination is to place the relational aspects of administrative tasks outside of the professional role. As the extract from the field notes points out, what remains off-the-record –and therefore out of the “official discourse”- is what highlights the relational aspects of administrative work.

### **Distributive Justice and the Gatekeeper**

Administrative clerks, when reflecting on their everyday practices, negotiate with competing ideas about equality and make a especial effort to gloss over any suspicions of giving favourable treatment to some people (be it Gitanos or any other group, for example elderly people). When equality is understood as taking into account the specificities of the patient (similar to the idea of doctoring that Annemarie Mol characterized in ‘The Logic of Care’(2008)) and therefore the resulting interaction with the patient may differ from the standardized response, there is a need to justify that this tailored handling is also based on fairness and not on the personal bias of the administrative clerk. Social justice and distributive justice are intermingled: with standardized practice there is no risk of distributing resources in an unfair way, as ideally everybody, regardless of who they are, receives the same attention. But when

attention is tailored to the needs of the patients, the possibility of unequal distribution appears. Different ways to justify this apparently unfair distribution are put in place, like explaining it as a future gain or to avoid conflicts, for example. The next quote from one interview with an administrative clerk reflects upon these ideas:

‘I cannot just tell them you have to go and ask for something or other, somewhere or other... no, it does not work like that; look you have to go and they are going to give you a paper like this one and you show the actual paper, ok, then they (the patients) have already seen the paper form and when they give it to them they already know that it is the right one.. If you do not show it to them and they get a different one... [...] It is not big deal to do that, it is all the same to me, really, it’s nothing and before, at the beginning people (patients) were very reluctant, very unwilling and it was not that they were aggressive, but they were very defensive, like expecting to get a no here, and at least with me... I know I have dedicated a lot of time; it is true, I mean I may have spent 15 or 20 minutes ... my colleagues were saying, damn it! You spend a lot of time... and I replied but I am sowing for the future. And little by little they (colleagues) start understanding me.’<sup>51</sup>

The guiding principle in cases like the one in the quote above seems to be to facilitate access, albeit by spending more time than usual or having to provide extra explanations. If primary healthcare administrative staff are the gatekeepers of the healthcare system, facilitating access corresponds to a conceptualization of distributive justice as universal coverage; everybody has the right to access healthcare and the task is to make this right possible. The gatekeeper’s role would be oriented towards assisting in this access. On the other hand, and at the opposite extreme of the facilitator-gatekeeper position, distributive justice can be conceptualized as filtering out those patients that are not entitled to healthcare (or filtering out the wrong

---

<sup>51</sup> ‘Efectivamente, yo no puedo llegar y decirle tienes que ir a pedir el no se qué no se donde tal, no mira vas y te tienen que dar un papel como este y le enseñas uno de muestra, vale, entonces ellos ya ven el papel, cuando se lo den ya saben cual es, si tu no se lo enseñas y le dan cualquier otro [...]no te cuesta nada, la verdad que no y antes a principio como que la gente era muy reticente, muy reacia, y además venían ya no agresiva, pero venía ya a la defensiva, aquí va a tener el no, y yo por lo menos conmigo... yo también es verdad que les he dedicado mucho tiempo, o sea yo me he podido tirar 15 o 20 minutos... que mis compañeros decía, joder, te tiras... les oye, que estoy sembrando para el futuro... ahora ya me van entendiendo, joder’

reasons to ask for healthcare). As was developed previously in this chapter, the tendency is to confuse deservingness with entitlements and therefore to curtail the rights of people entitled to healthcare but who in fact find not so evident obstacles to gaining access to it. In part, those ‘intangible obstacles’ (Larchanché 2012) have a lot to do with the favouritism of the obstructer-gatekeeper role over the facilitator. To be able to make judgements about who is deserving and who is not, the administrative staff (and other healthcare workers alike) build upon shared popular representations to justify their judgements.

In a reference document on the topic of health and the Gitanos community issued by the Ministry of Health, the difficulties in the relationship between Roma and healthcare workers are analysed (MSC and FSG 2005). In the document, these difficulties are described as the result of what they call ‘mutual prejudice’ between Gitanos and healthcare workers that leads to a relationship based on mistrust (2005, 18). The reasons for this mutual prejudice are explained as the product of:

‘Historical prejudices on which the relationship between the Roma community and the rest of society has been based. Individual negative experiences, which tend to fuel prejudice while positive experiences, perceived as exceptions to the rule, do not have a counterbalancing effect’ (2005, 18).

Bearing in mind the historical prejudice upon which the relationship with Gitanos is established in Spain, it is not hard to understand why Gitanos take one helpful person as a reference at the admission desk. The reference clerk is, as the document contends, ‘the positive experience perceived as an exception to the rule’. Other research has already highlighted the importance of establishing a relationship of trust with Gitano patients (Sàez Sellarès and López Catalán 2009; Ayala Rubio 2008) but they have primarily considered the patient-physician relationship, leaving administrative staff outside of their studies. My point is that establishing a relationship based on trust with the administrative staff has dual importance: first, it guarantees that access is not curtailed by negative representations of Gitanos, and second, it creates a ‘positive experience’ that may not counterbalance the negative effect (as the ministerial document states) or, on the contrary, it may set a precedent for other trusting relationships.

When Gitanos are identified not through the use of stereotypes as a protocol, but through familiarity with their situations, it is possible to acknowledge the difficulties they may find in the bureaucratic process necessary to access healthcare. Once these difficulties are identified, they can easily be handled and even simplified, as the administrative clerk from the previous quote explained. These bureaucratic difficulties are not specific to Gitanos, but it is necessary to bear in mind that the obstacles they experience in healthcare arenas may be similar to those they experience in other public institutions. Helping Gitanos to overcome these difficulties is crucial in the process of accessing healthcare.

My characterization of gaining acquaintance with Roma and Gitano patients as a process of identification does not mean becoming a friend or taking a paternalistic attitude towards Gitanos. When I refer to acquaintance I mean going beyond the symbolic boundaries that separate Gitanos from the non-Gitanos population. These symbolic boundaries rest on the stereotypes of Gitanos and they are permanently renewed by the use of stereotype as a protocol to treat Gitanos. Michael Herzfeld defines stereotypes as follows: ‘Stereotypes are one of the currencies of social life. They represent long-established prejudices and exclusions, and, like nationalist ideology itself, they use the terms of social life itself to exclude others on cultural grounds’ (1993, 72). I use acquaintance to refer to the act of going beyond the stereotypes and approaching the cultural Other, and opening the possibility of a perception of the ‘Other’ that is not based on the cultural grounds that exclude her. Acquaintance refers to abandoning the spatial trope that locates Gitanos outside of the realm of citizenship.

## **Concluding remarks**

In this chapter I have exposed the different aspects that intertwined in the way Gitanos access healthcare. Despite the lack of attention usually paid to the work at the admission desks in medical anthropological research<sup>52</sup>, the different examples I

---

<sup>52</sup> There are some exceptions, for example Khiara M. Bridges ethnography of a public hospital in New York City (Bridges 2011)

provide show how the admission desk is a crucial negotiation site, where fundamental aspects of citizenship (such as access to healthcare) are granted or denied. The admission desk is far from a neutral space where laws and rules are implemented straightforward: as I show, in the admission desk's practices, there is enough space for interpretation and manoeuvre in the implementation of a rule in multiple different ways. Issues such as the identification of patients as Gitanos, the availability of resources and the different roles as gatekeepers that the administrative clerks adopt when attending to Gitano patients, mould the kind of access to healthcare. While the prevailing collective imaginary about Gitanos encroaches the way the admission desk workers perceive Gitano patients, the same administrative clerks enact different 'repertoires of practice' (Pols 2006) based on the situated ways of inhabiting different understandings of their professional role.

It is at the encounters between Administrative clerks and Gitanos that access to healthcare can be granted or denied, underlying the relational aspects of citizenship (Pols 2016). It is at these encounters where cultural difference appears as a means to understand the tensions when distributing scarce resources. When resources are short and decisions about who to prioritize have to be taken with little information, it is then when the stereotypes about Gitanos —those that represent them as illegitimate population- appear and become preponderant for the decision making process. Despite these kind of practice (What I call 'stereotypes working as a protocol') may occur in contexts where there is no competition for scarce resources, my fieldwork experience was that these kind of encounters were much more frequent during periods of high demand and limited resources. Gitanos are thus portrayed as what I call "ill-timed patients" as the admission desk workers continuously complained about the urgency and immediacy in being attended Gitanos ask for. This temporal incongruence between the patient and the admission desk workers ultimately signals to what is consider the cultural difference of Gitano, and the frictions that it unravels.

However, the 'stereotype working as a protocol' is not the unique kind of practice that takes place at the admission desks where I conducted fieldwork. There are other instances when the stereotypes are downgraded and loose their explicative power to delegitimise Gitanos as full-right citizens. These practices, while acknowledging the same kind of stereotypes about Gitanos, trespass the boundaries that these stereotypes create and mould the practice to the patients' needs, without questioning notions of

legitimacy. In the next chapter, I investigate the kind of ‘repertoires of practices’ enacted in the encounters between physicians and nurses and Gitanos, and the different meanings of cultural difference in the specific social space that consulting rooms are.



## Chapter Three: The Consulting Room

'Friday consultation

Again, another varied consulting afternoon. I arrived late and I saw two young women already waiting to be called in; they looked like Gitanas, maybe. When I walk in, Ana (the physician) is attending to a young immigrant couple: he has been living here for nine years and brought her with him just four months ago. They want to have a baby so they are asking Ana if there is something they need to check because she has not managed to get pregnant yet. Ana explains that they should keep on trying, that trying for up to one year is normal (I liked that she did not explain it with statistical terms) and asks her about the vaccines she got as a child while writing out a folic acid prescription. Then, Ana continues encouraging the woman to learn Spanish, praising the husband's ability to speak Spanish. He does not have an appointment but Ana checks his ear anyway after registering him in the electronic agenda. They leave and the two young women who were waiting come in together: just one of them has an appointment; she needs a prescription filled for her migraine treatment. Ana tells her that she thought she was doing better because she has not seen her for a good while, but the young woman replies that it is because she is going to the emergency room and the emergency primary healthcare centre because its opening hours are more convenient for her. Still, she tells us that she has gone to the hospital to schedule an appointment with her neurologist but the first free appointment was in four months, so she will go and see another neurologist who had free appointments earlier. We joke about the surname of the neurologist (Dr. Acid), which initially we took as a nickname but it was the actual surname, and the patient says that she is a very good neurologist and everybody wants to go with her, which is why she does not have appointments. At some point during the consultation it is clear that her headaches are related to some stressful events she is coping with lately, something that the companion (which

afterwards I found out was the sister) confirms. Ana tells me about the patient's parents and then the sister begins asking for things for herself, but Ana tells her to go to the admission desk and ask for an appointment, because she never comes to the consultation so it is better to schedule an appointment and check everything at once. They leave the consultation and I ask Ana if they are Gitanas, and she confirms it so I leave the consultation to ask them for an interview. After one hour I come back to meet Ana in the coffee room. She asks me how it went and I explain that they were really nice and that we had a nice chat about them and their children. She is surprised, and tells me that she did not know that the younger sister had children, that the older one is now living with the parents and that they are not at their best right now. Ana tells me she usually bumps into them in the street when she returns home from her yoga lessons and they are gathered outside of one of the evangelical churches in the neighbourhood. She tells me that they are beautifully dressed and made up; for her they look like models or "transvestites", and she laughs. Then the cleaning lady and the security guy who are in the coffee room, too, enter into the conversation, which turns to talking about a TV program about Gitanos called "Palabra de Gitano" (Gitano's Word). The cleaning lady describes the last episode she watched to us; it was about a wedding and they displayed all the cultural elements associated: the handkerchief ritual and those shiny dresses... Ana interrupted her and told us about a patient who invited her to a wedding and who told her that those Gitanos on TV were very weird, that they did weird things. That nowadays weddings last only two days, not three.

Back in the consulting room after the break, we attend to a little bit of everything: some patients from South America, from India, young Spaniards... Ana is cordial and nice to her patients. It's a good afternoon; it is summer, Friday, we do not need to rush and we take our time with each patient. An old Gitana woman came to the consultation, complimenting Ana as she walks from the door to the seats. She is dressed all in black because she is in mourning for someone, while her companion is wearing a colourful flowery dress. Ana tells her that she (the patient) loves her too much but visits her too little, that her last visit was six months ago and that she does not even come for prescriptions. Like most of the old women she has some sleeping pills and tranquilizers, noted as chronic treatment, but she does not want anything from us. Ana tells me that she already considers her a lost cause, even if she has a rapid heart rate and high blood pressure. We try and negotiate her letting us carry

out some tests, but it is in vain. The companion tells us that she (the patient) will not ‘set a toe in the hospital’ (“*esta ni un dedo pone en el hospital*”). We insist and give her an appointment for the following week, but Ana tells me that for her she is a lost cause. At the last minute Mario and Conchita knock on the door: they come because Conchita had a skin biopsy at the hospital in the morning. Ana is worried that there is something else that will eventually show up, because she sees that Conchita is getting worse. They are an adorable old couple, very friendly, that continuously invoke their faith in God. He is quite deaf so she usually speaks and loudly makes jokes about him. They’ve come to tell Ana that they are going to Valencia for some days to visit their daughter, and to check Mario’s bronchitis; he needs an aerosol treatment and goes to the treatment room. When he is done with the treatment and back in the consulting room he tells us about Conchita’s brother who was a Flamenco singer and how they used to work for him, Mario playing the guitar and Conchita arranging the sets. I go to the toilet and there I meet Rocio, the nurse who is in charge of Conchita and Mario and who just gave him the aerosol treatment. She tells me about their daughters, who got married when they were twenty years old and whose husbands are making them work a lot. She tells me that Mario is not happy with his sons-in-law because of that, and that he sold their apartment to give the money to his daughters but he’d rather marry his daughters off to Payos. She adds that Mario treats Conchita very well, that he has always worked and provided for her. I go back to the consulting room where Ana is tidying up, I pick up my stuff and we leave the healthcare centre. It is ten past nine p.m. and the orderly is already waiting for us to lock up the centre.’

(Extract from my field diary)

## **Introduction**

I decided to begin with this extract from my field diary because it illustrates some of the relevant aspects I aim to analyse in this chapter. From this account of my observation of just another ordinary physician’s consultation on a Friday afternoon in the summer, we can get a sense of the kind of “social space” that the healthcare centre is: the diversity of patient-physician encounters and established relationships, the varied reasons to seek care at the healthcare centre and the organizational tempo

in which these encounters take place. From the extract of my field diary we get a first idea of the kind of tools, routines and roles deployed in consultations. The healthcare centre is not only constituted as a space of socialization between clinicians and patients but, as the extract shows, there are multiple relational webs among healthcare personnel and among patients, which ultimately influence the way care is provided.

As in the previous chapter, I aim to analyse how the idea of “Gitano cultural difference” is operationalized in the context of clinical encounters with physicians and nurses. I aim to understand the different mechanisms used to identify Gitanos and the practices that these identifications give rise to. If at the admission desk cultural difference often helped to justify practices of exclusion based on the construction of Gitanos as illegitimate patients, in this chapter my intention is to unpack the meanings and uses that cultural difference brings up in consulting rooms. As Sylvie Fortin puts it, ‘[c]ulture underlies our understandings and interactions, but its components fluctuate and are engaged differently according to issues at hand’(2008, 175). Although admission desk personnel and physicians and nurses share the same institutional rules and, at least in theory, they work together, sharing a mutual purpose (to help the population they are responsible for to attain the best health status possible), their responsibilities and perspectives on how to achieve that purpose are different. These diverse perspectives influence the way physicians and nurses resort to Gitano cultural difference in their everyday practices, and they subtly modify the meanings of cultural difference from those manifested at the admission desk.

In this chapter, I analyse the practices of the physicians and nurses that work at the primary healthcare centres conjointly without specifically analysing the differences among their professional roles. There are two reasons why I decided not to differentiate: first, both physicians and nurses share the same biomedical framework and understand their work as complementary<sup>53</sup>. They share organizational norms

---

<sup>53</sup> I did not find nurses’ vindication of their professional role as providing “holistic” care in opposition to the physician’s biomedical model but in two interviews with nurses that, besides of their clinical work, were involved in undergraduate nursing programs. At primary healthcare centres, the spectrum of nurses’ practices was as varied as those of physicians. There are other complex issues at stake, such as the background of some of the nurses, who, tired of the changing shifts at the hospital, move to primary healthcare, seeking tranquillity and comfort in their work. The study of this phenomenon

and some hierarchy in their relationship, too. However, at the primary healthcare centres where I conducted my fieldwork, the traditional hierarchical relationship between physicians and nurses was downplayed by the organizational structure. Similarly, among the physicians, they come from different backgrounds: some of them are paediatricians; others did not specialize as general practitioners but as something else. Thus, there are multiple variables that influence nurses' and physicians' practices but also physicians themselves come from different backgrounds. Secondly, during my fieldwork I realised that despite having different professional roles, the practices and processes of identification of Gitanos were not substantially different at the nurse's or physician's consulting room. Therefore, instead of focusing on those professional differences<sup>54</sup>, which could obfuscate the analysis, I decided to explore what the different representations were of their roles as clinical workers in primary healthcare. Focusing on their role as clinicians at primary healthcare does not mean that I do not pay attention to other factors influencing the way they understand their role –as I will show in the analysis of the subsequent vignettes- but for analytical purposes it is more relevant to prioritise their position within the healthcare system as frontline clinicians.

Similarly to the admission clerks, primary care clinicians are 'street-level-bureaucrats' (Lipsky 1980) inasmuch as they provide services within the public healthcare system and grant access to specialised services. Besides, they occupy the lower ranks of the clinical hierarchy, constituting the bottom of the healthcare system structure. The role of primary healthcare as the cornerstone of the healthcare system, frequently highlighted in technical documents and political discourse, does not translate to either social recognition or institutional support. Chronic underfunding of the primary healthcare network (as shown in chapter one (Simó and Gervas 2012)) and the clinicians' position as gatekeepers to access specialized services mean that these physicians frequently refer to their work as the "trenches" (*"las trincheras"*) of the healthcare system. During my fieldwork, the use of war metaphors to refer to their

---

exceeds the purpose of this dissertation, but I think it was important to mention it to understand my decision.

<sup>54</sup> In my original research plan I envisaged to look at the differences between physicians and nurses in the provision of care to Gitanos and Roma

ordinary practice was common, as was some clinicians' recourse to jokes to show their disappointment with the professional position they had: playing on words with the so-called 'patient-centred-care'<sup>55</sup> they refer to their practices as "enemy-centred-care". What I investigate in this chapter is how these clinicians make sense of their role on the lower rungs of the clinical hierarchy (and of the healthcare budget expenditure) and in close relation with the community they provide services to, while managing complex situations within a web of constrictive bureaucratic and management rules (and with little professional recognition). This role as primary healthcare clinician, and the multiple ways to make sense of it, encompasses the tensions and anxieties that abound in primary healthcare.

There are multiple and opposing forms of logic that simultaneously coexist in primary healthcare centres and whose entanglements are ultimately represented in the different 'repertoires of practices' (Pols 2006) that take place in the consulting rooms. Jeannette Pols defines 'repertoires of practice' as 'specific actions, ideals and knowledge, forming modes of ordering' (Pols 2006, 79). Organizational logic and management pressures at the consultation, institutional demands to reduce waiting lists/sick leave times/ prescription expenditures, biomedical models that focus on the biological and leave out the biographical, different ideals about social justice and equity in the provision of care... all these different actions, ideals and knowledge sketch an array of professional roles' positions (or modes of ordering as Pols calls it) that clinicians inhabit in situated practices. In the previous extract from my fieldwork diary, Ana responds differently in two similar situations (whether to attend to the patient's companion without having scheduled an appointment) by placing herself in different positions within the spectre of her understanding of what entails being a good professional. In this way, Ana's practice (and clinical practices in general) represents a good site to investigate 'ordinary ethics' as Ana bases her decisions 'on the conjunction or movement between explicit local pronouncements and implicit local practices and circumstances' (M. Lambek 2010, 7). The consulting room as a social and political space is a good site to investigate that interface between the

---

<sup>55</sup> Patient-centred-care is a widely used expression in clinical arenas but it is poorly defined. Broadly, it makes reference to healthcare that takes into account patient's perspectives and that is meaningful to her.

explicit and the implicit in the encounters that give meaning to the idea of cultural difference. As Mol and Berg argue, ‘Medicine is not a coherent whole. It is not a unit. It is rather an amalgam of thoughts, a mixture of habits, an assemblage of techniques’ (1998, 5). It is through the ongoing practices, and not from an outside vantage point, that I aim to analyse how cultural difference is mobilised in different situations by some participants and not others, and the different meanings that are conferred.

The chapter is structured as follows: first, I provide some context about the institutional and organizational logic that underpins clinical work at primary healthcare centres. Secondly, I explore some of the representations that healthcare workers hold about Roma and Gitanos, and how they discursively construct Roma as a new version of an old patient (Gitanos). Thirdly, through three ethnographic vignettes, I analyse different clinical encounters that account for the different ‘repertoires of practices’ that I found during my fieldwork.

## **1. Configurations and Representations**

### **1.1 Five Minutes Today, Years to Catch Up: Organizational Arrangements**

The displacement from the admission desk to the consulting room implies moving from a public space (where nevertheless the disclosure of private information may be necessary) to the quintessential space of privacy. There are several types of consulting rooms at healthcare centres – for nurses, general practitioners, paediatricians, midwives, dentists- and despite their differences, all of these consulting rooms share a duty to preserve confidentiality and privacy. Professional secrecy is an imperative and whatever is disclosed at any consultation remains in the consultation, in theory at least.

The confidentiality of the consulting room derives from a professional role with its own understandings about healthcare, disease and the body. In this professional arena, which is that of biomedicine, confidentiality is cherished, patient autonomy is encouraged and collaborative work is desired. The traditional bedside manner of the old general doctor still oozes from the colloquial names with which people refer to

general practitioners: *médicos de cabecera* (literally headboard physicians). Similarly, their professional activity is still regulated by the four core ethical principles of biomedicine: autonomy, beneficence, non-maleficence and justice. But their practice itself has changed significantly, at least in appearance. Now, most of the primary healthcare clinics are new buildings with quasi-identical designs, featuring rows of consulting rooms that are as regular as they are impersonal. Most of the consulting rooms are divided in two by a mobile curtain: in the area closer to the entrance door there is a desk with the omnipresent computer screen and all of the necessary stationery, proof of the amount of bureaucratic work that is usually carried out there. If it were not for the now obsolete negatoscope<sup>56</sup> hanging on the wall behind the desk, that space of the consulting room could be any other institutional office. The examining table is hidden behind the curtain, at the back: as a reminder of the confidentiality of the space, the patient's body is protected from unexpected gazes. Behind the curtain classical physicians' equipment to measure, listen to, observe, palpate or explore any of the features of the patient's body is displayed. A trolley full of boxes with gloves, tongue depressors, surgical knives, syringes, gauze, urine test strips, pregnancy tests, glucometers, thermometers, scales, and so on, sit next to the examining table, and in front of it there is a sink for the physicians to wash their hands after having contact with the patient.

The choreography in the consulting room usually goes as follows: the physician goes out to the waiting room and calls the patient, who then enters the consulting room and sits in the chair in front of the physician's desk. The patient explains his reasons for requesting an appointment, the physician asks questions to try to understand the problem; they both move behind the curtain and the physician explores while asking more questions or explaining things to the patient. He also measures parameters or just listens to the patient. The intervention of a nurse may be needed, in which case the physician goes to the adjacent nurses' room through one of the side doors of the consulting room. Once they have finished dealing with the body, they go back to the desk, each on his side, where the therapeutic plan/sick leave/record/referral to the specialist is explained, questioned, agreed or negotiated. Sometimes this is the

---

<sup>56</sup> A negatoscope is a device like a lamp to display X-ray films. They are out of use because most of the X-ray are now displayed electronically on the computer screen.



moment when hidden worries surface, or when anxieties, forgotten pains or questions that open up new scenarios are either paid or denied attention. It is also the time to look back at the screen computer and write up the episode in the patient's clinical records, print prescriptions, referrals or sick leave confirmations and schedule a new appointment if needed. Then the patient leaves the consulting room and in a few seconds a new one is sitting in the chair, ready to repeat the steps of the previous one with his own peculiarities.

Obviously there are variations in this basic choreography: some patients do not need to be physically examined, and others need to return to the consulting room after receiving immediate treatment; sometimes this takes a few minutes and for others it is more complicated and needs more time. There are personal styles among physicians and nurses too: some physicians and nurses tend to allow the patient to express herself, while others are more directive; some physicians and nurses are quick to scold patients when they do not take their advice "by heart", and other physicians or nurses are more indulgent. There was also variability within the same profession, depending on the workload they had: during the months of the flu epidemic in winter, it was much more difficult to have time to deal with several problems in one consultation, and physicians focused on addressing the acute problem. The workload decreases during the summer months and at that time of the year physicians and nurses have time to revise their clinical records and put them in some order. Good days were those when the amount of 'important' consultations was balanced with petty bureaucratic tasks that did not demand too much time. But still, during my fieldwork, this choreography took place thirty times per day on average in the physicians' consulting room. Patients are scheduled in six- or seven-minute slots in the professionals' agendas.

Robert Alfred Hahn (Hahn and Gaines 1985), in his hospital ethnography with an internal medicine specialist, contends that time management is integral to the specialist's working day: 'Barry is oppressed by two sorts of temporal constraints. Too much to do in the allotted time, and the urgency for action imposed by what are too often literal "deadlines". Time is differently shaped accordingly: excess draws it out, imminence intensifies every moment'(1985, 62). At the primary healthcare centre, the management of time was also shaped by the temporal constraints of the few minutes allotted per patient whereas attending to life-or-death situations was rare. Still, the

organizational pressures that bear on clinical work mingle with the “therapeutic time” that orchestrates clinical interventions. “Therapeutic time” can be defined as the temporal framework that determines timely interventions to stop the natural forward-moving course of disease and thus, to produce therapeutic effects of different kinds: avoiding the disease’s manifestation in the case of preventive measures, curing the disease or reducing its effects in the case of treatment processes.

It is noteworthy to investigate the effect that the conceptualization of their work under a therapeutic time framework has on primary healthcare clinicians. As Paul Brodwin notes, ‘The imperative to act in therapeutic time lies near the centre of health care as a moral enterprise, and it forms part of the disposition of frontline clinicians’ (2011, 192). As the extract from my field diary shows, the physician accommodates her practice to the organizational pressures, or their absence as happened that Friday afternoon. But also she worries about futures that she anticipates in the present (with Conchita and her skin biopsy, for example) following the therapeutic time framework, and gives up in the face of her patients’ stubborn refusal to abide by this same therapeutic temporality (with the patient who did not want to have any tests). Moreover, in a subtle but interesting way, Ana also uses the encounters to show her patients the institutional and organizational time framework: she did not attend to one of the Gitana sisters because what she asked for was not urgent but also because Ana wanted to differentiate her consultation from the emergency services that her sister frequently visited. Ana wanted to make clear that at the healthcare centre it was important to schedule and plan in advance.

Finally, we can consider another aspect of time that is relevant in clinical practice. In the previous notes from my fieldwork diary the sense of lasting relationships between clinicians and patients is present in diverse ways. The physician knows the patients and their family, she knows when someone comes regularly or not. Patients come to tell her that they are going to be away for some days or weeks... the nurse knows the family structure and the different important life events well. This relationship established over time between the patient and the clinician is what Alpert and Charney dubbed longitudinality (1973). Barbara Starfield (1998), one of the thinkers and advocates of primary healthcare, considers longitudinality to be one of the most important characteristics of primary healthcare, as it presupposes the existence of a regular source of care and its use over time, reducing inequities. The idea that the

physician and nurse know about the life course of their patients, creating a trusting relationship over time, permits a management of time that compensates present scarcity with the possibility of continuity in the future. One of the physicians put it this way: *‘Okay, today you only have five minutes (or even less) but you have the years coming to catch up’*. The electronic clinical records system evokes this life course approach in primary healthcare as well: structured by episodes, there is a timeline that begins with the patient’s birth date, and clinicians note the events that are relevant. On the patient’s timeline, primary healthcare clinicians write different episodes that correspond to clinical diagnosis and which are codified under the International Classificatory Primary Healthcare system CIAP-2 (or ICPC-2 in English). Thus, clinicians translate the lives of their patients into a life course spotted with standardized diagnoses and each diagnosis has that patient’s particular story associated with it.

If longitudinality is one of the pillars on which primary healthcare is based, temporary and locum workers have to adapt to a healthcare structure based on a requisite – longitudinality- that for them does not exist. It is difficult to decide how to deal with complex patients in six minutes when their clinical records are new to the physician or nurse. It is also complicated to be aware of the patient’s context if healthcare workers are not familiar with the neighbourhood -a familiarity that is usually gained by spending time in the area. If we bear in mind the high levels of job precariousness and the amount of temporary contracts in the public health system, and specifically in primary healthcare, longitudinality is under threat and has been reduced by progressive labour flexibilization and precarious work triggered by budget cuts. Electronic clinical records may become a useful tool for temporary workers and locum; still, these records are not always as clear as they could be. Time limitations and concerns about privacy (once it is written in the clinical records any primary healthcare clinician can read it) cause some life courses to be dotted with standard diagnoses but little information about those episodes is available. However, the precarious conditions and high rates of temporary workers in primary healthcare leave a mark in the electronic clinical records, as one young “precarious” physician wrote:

‘The locum writer, or precarious physician, can only aspire to write someone else’s story [...] You can barely read the locum’s silences... it looks like a story build up with pages rescued from the fire [...] There are consultations ruled by temporary workers, in which the clinical records resemble an “exquisite

corpse”. That is why some of us dream about getting permanent positions, so we have time and the keys to be able to write between lines, which is where the sense of the story is’ (Benedicto Subirà 2013 my own translation).

In his reflexion, this physician beautifully signals the effects that the lack of longitudinality has not only on clinical records, but also on the possibility of providing patient-centred care.

So far, I have explained how time, and its multiple aspects, is a core dimension of primary healthcare. Organizational, therapeutic and longitudinal time frameworks are entangled in the provision of care at the healthcare centre. Perhaps because of the organizational pressures that transform time into a scarce resource (either by reducing consultation time or longitudinal care) or the therapeutic mandate to intervene in the disease’s course in a timely manner, time was a central issue in both healthcare centres where I conducted fieldwork. As I will analyse in the next section, and subsequently with examples of specific encounters, how the particular temporal frameworks used by primary healthcare clinicians affect the representations these clinicians hold about Gitanos and Roma. Next, I analyse these representations and how clinicians discursively construct Roma and Gitano patients.

## **1.2 “Hyperchondriac” Patients: Cultural Repertoires in Regard to Gitanos in Primary Healthcare Centres**

To analyse the clinical encounters between Gitanos and nurses and physicians it is important to bear in mind the cultural repertoires (Michele Lamont and Small 2006) used by these professionals when they encounter Gitanos. In chapter one I explored the cultural repertoires in regard to Gitanos in Spanish society, which mainly revolve around their representation as ‘individuals to be corrected’ because of their innate inability to comply with the basic conviviality rules. At the healthcare centre, these broad cultural repertoires intersect with the different repertoires of practice (Pols 2006) of administrative staff or clinical staff, subtly transforming the wider representations through the experience of healthcare workers and their situated contexts. Thus, at the primary healthcare centres the cultural repertoires in regard to Roma and Gitanos mainly revolve around their non-compliance with the norms, be these norms social, institutional or biomedical.

In the research conducted by Sàez Sellarès and López Catalán (2009) about the Romanian Roma's relation with public healthcare services in Catalonia they signal that the "double stereotype"<sup>57</sup> of the Roma population has a counterpart in clinical settings:

‘On the one hand, there is an image about Roma people being more reticent to use healthcare services. On the other hand, it is important to notice that another contradictory stereotype exists, too. A stereotype that is shared with other populations, which are characterized as very demanding at clinical settings and in general’<sup>58</sup> (2009, 162).

The double stereotype of Roma and Gitanos as both misusing/non-using healthcare services was one of the shared narratives about Gitanos among physicians and nurses in my research context. It was one of the main topics that appeared in most of the interviews and discussion groups: on the one hand, physicians and nurses acknowledge that Gitanos do not access healthcare services, while on the other they refer to a differentiated and disorganized use of these same services:

“Okay, let's say that I do not see many pregnant Gitanas in my clinical practice because they do not come to us; that is the problem. The big problem that we have is that they have not embraced the need for a follow-up; well, they come for the blood test, for some other stuff”

The idea that Gitanos are very demanding was mainly framed in terms of the immediacy with which they want to be attended to, and the admission desk staff, physicians and nurses highlighted this urgency as the salient difference of Gitanos. In one of the sessions, a physician told us the reason of this: she shared with the group that a Gitano explained to her that the need for immediate attention from physicians was due to the fact that Gitanos are “hyperchondriacs”. In this involuntary mistake (obviously the patient meant hypochondriac) this Gitano was conflating both of the

---

<sup>57</sup> This double stereotype consists of the phenomenon that the Romanian Roma population goes simultaneously through processes of social visibility and invisibility, prevailing the negative visibility in the media due to their informal activities.

<sup>58</sup> ‘D’una banda, existeix la imatge de que la població rom, de vegades, és molt reticent a utilitzar els serveis de salut. Per altra banda, cal apuntar que també existeix un estereotip en direcció contrària, compartit amb altres poblacions, que els caracteritza com una població molt demandant, en la pròpia consulta i en general’

main representations of Gitanos held by primary healthcare clinicians: the substitution of the hypo prefix with hyper highlights Gitanos being very demanding while the word retains its meaning of suffering from imaginary ailments. When the physician shared this anecdote in the discussion group, the rest of the participants agreed with the descriptive power of the neologism (and shared a chuckle about it).

Beyond Gitanos' representation as not complying with normal organizational timing, they are represented as not complying with treatment norms, as the next extract from an interview illustrates:

In a hurry, and this and that [...] I HAVE TO BE ATTENDED TO RIGHT NOW! (the Gitano patient shouting) Come here, ok, let's see [...] when was the last time you measured your blood pressure? [...] come here, I am going to give you a full check-up [...] and when he was leaving the consulting room he said to me, 'thank you very much, doctor, because I had never had a full check-up' [...] it has been two years since then and still he does not take his pills and he completely bloody ignores me"<sup>59</sup>.

The image of Gitanos as non-compliant patients is grounded both in the personal experiences of physicians and nurses and the category of non-compliant patients available in this context. Despite most of the nurses and physicians claiming that adherence to (or compliance with) treatment is not a problem specific to Gitanos, during the interviews all of them referred to it and gave some examples from their practices. The non-compliance was explained either in cultural terms (see first quote below) or as being due to a lack of resources (both intellectual and material) (see second quote):

'I have a lot of HIV+ that abandon treatment or that do not take treatment forward because of the stigmatization that it entails in their culture'.<sup>60</sup>

---

<sup>59</sup> "la prisa tal tal tal QUE TENGO que entrar ya!!!!, QUE NO SE QUE QUE NO SE CUANTOS, ven pa acá, a ver cuándo te has tomado la tensión cuando no sé qué, cuando no sé cuántos ven que te voy a hacer un reconocimiento cuanto sale me dice, muchas gracias doctora porque esto no me lo habían hecho nunca...luego dos años sigue sin tomarse las pastillas ni hacerme ni puto caso"

<sup>60</sup> 'yo tengo muchísimo vih que abandona tratamiento o que no hace tratamiento por la estigmatización que supone eso dentro de su cultura'

‘Besides getting them to accept treatment, I struggle to get them to understand it, to adhere to it, to understand [the medication]’.<sup>61</sup> ‘We would need a comparative study because I have non-compliant payos too. People who, I mean that [...] it is not their main characteristic, I think they do what they can’.<sup>62</sup>

‘With chronic conditions the patient does not take on responsibility for his condition; what he wants is to come here and for you to work it out, for you to prescribe some pills [...] that he may take or not [...] then, anything that needs a little bit of effort on his part, I mean, that it needs him to do this or that, he won’t. I mean this happens with everybody but with them (referring to Gitanos) much more, come on! A huge difference with the rest of the population’.<sup>63</sup>



Figure 6. Non-compliant patient.

A different example from the spectrum of non-compliant patients: an old person who cannot physically adopt the right posture to fit in the biomedical standards for a good quality RX. (In the image the label says: non-collaborative patient)

---

<sup>61</sup> ‘Para mí es muy difícil conseguir el que, aparte de que acepten la medicación, el que sepan, el que la mantengan, el que la comprendan’

<sup>62</sup> ‘habría que hacer un estudio comparativo porque también tengo payos incumplidores, gente que o sea que tan... que no es su característica principal, yo creo que hacen lo que pueden’

<sup>63</sup> ‘Sobre todo en la enfermedad crónica el paciente no se hace responsable de su enfermedad, él lo que quiere es venir aquí, que tú le soluciones la papeleta, que le mandes las pastillas que se las tomará o no, ... eso que se las tomará o no se las tomará pero él no se hace responsable de su propia enfermedad, sabes, entonces todo lo que conlleve esfuerzo por su parte, o sea que conlleve que tiene que hacer tal y tal pues no. Vamos que esto lo hay en general, pero sobre todo ellos vamos muchísima diferencia con el resto de la población’

The representation of Gitanos as non-compliant with the biomedical model of health, disease and treatment speaks of the alleged unruliness of Gitanos in the language of healthcare professionals. Ultimately, this unwillingness to collaborate with clinicians is built on and reinforces the idea of voluntary exclusion, or as the medical article I quoted in chapter one called them, “self-marginal people”. As other authors have already signaled for the Spanish case and elsewhere in Europe (Gay y Blasco 2016; Picker 2016) it is commonsensical to understand Roma and Gitanos’ spatial segregation as a consequence of their abject culture, glossing over long-term housing policies and mechanisms of surveillance which have contributed to Gitano and Roma segregation. The non-compliant Gitano patient is more proof that Gitanos, despite the efforts of healthcare workers to “integrate” them, are incapable of being part of society. Furthermore, it is important to note that framing Gitanos as “self-marginal people” or non-compliant not only underlines Gitano incapacity to follow healthcare rules but also ‘the benevolence of the democratic state in attempting their redemption’(Gay y Blasco 2016, 448).

Clinicians resort to the trope of integration used in the Spanish context to talk about government plans aimed at Gitanos and Roma, too. Firstly, the trope of integration serves to differentiate those Gitanos that are considered ‘normalized’ from those who live in settlements and substandard housing, who have not embraced the integration programs offered by different institutions, which is proof of the abject cultural difference of Gitanos. Healthcare workers also associate Gitanos and Roma with shantytowns. As one physician told me ‘I do not know where the Gitanos live round here but I would think most of them live in the settlement or in those shabby houses round there’<sup>64</sup>. Patients from the settlement could be from different backgrounds, but in the eyes of the healthcare workers most of them were Gitanos. So there is a clear distinction between those Gitanos who live in the settlement and those who live in the neighbourhood. For example, one of the physicians explained to me during the interview that before working in the primary healthcare centre that attends to the settlement she did not know any Gitano. She made a specification after making this statement

---

<sup>64</sup> ‘si porque aquí yo no sé dónde viven los gitanos pero me da la impresión de que la mayoría viven en Cañada...en casas de estas cutres de por ahí’.



‘There was drug dealing but it was under control, I used to attend to five or six in my consultation (Gitanos), but they were very controlled, very normalized and the rest of the population were people from the village, very respectful people, hard workers, very normal people... with a low educational level, but very respectful in an old fashioned way... as I put it; people who respect a basic number of rules. Their children have grown up with me, well, common working people, people who did... a lot of them studied, went to university and all that and some did not. People, most of them without problems, and then, when I arrived here the first days I was crying all the way back to my home, the first two months I waited until I was in my car and then I started crying... I arrived here and found a population completely mixed and it was the first time in 25 years that I was attending to non-normalised Gitano people’<sup>65</sup>.

This physician made a distinction between those Gitanos who live in the neighbourhood and therefore are “*normalised*” and the new situation in her new position where the population is “*completely mixed*” and she has to attend to non-normalised Gitanos. It is quite interesting that she also connects Gitanos with drug dealing but this does not represent a problem because it is under control and it seems that those Gitanos involved in it are ‘*very normalised*’.

Secondly, the trope of integration serves to discursively differentiate migrant Roma from Gitanos. The arrival of migrant Roma from Eastern Europe and their settlement on the outskirts of the city close to Gitanos, has reinvigorated the idea that self-isolation from Payos as well as living in precarious conditions is something intrinsic to Roma and Gitano culture, and therefore, something that confirms that Roma and Gitanos are intrinsically the same but in different “development” stages. The argument goes as follows: Roma live in the settlement with those Gitanos that did not want to integrate into majoritarian society through re-education programmes; they are incorrigible people from the settlement that due to their unruliness cannot

---

<sup>65</sup> ‘Había su droga pero muy controlada, veías a 5 o 6 en consulta pero muy controlados, muy normalizados y el resto era población que venía del pueblo, gente super respetuosa muy trabajadora muy normalita, con nivel cultural bajito pero educados a la antigua, como yo digo, de la gente que respeta una serie de normas. Los hijos que han crecido conmigo pues gente trabajadora normal, gente que hizo, muchos han estudiado, su carrera y tal otros no, gente la mayoría sin problemas entonces yo cuando llegué aquí los primeros días me iba llorando a mi casa, los 2 primeros meses, esperaba montarme en el coche y luego ya me ponía a llorar, y entonces llegué aquí me encontré una población totalmente mezclada y era la primera vez en 25 años que atendía a población gitana no normalizada’

live among Payos. Therefore migrant Roma are like ‘*our old Gitanos*’ (*nuestros Gitanos de antes*) as one nurse told me: they need to benefit from the same integration (or surveillance) programs as Gitanos, and some of them will manage to integrate thanks to the benevolent efforts of the state, in this case represented by healthcare clinicians.

This idea that re-education programs are needed for the new old Gitanos (Roma) reflects both their ethnic and their migrant identification and shows how new diversities lay upon old social organizational systems. The case of migrant Roma in Spain shows how they are represented as both outsiders but close to the differentiated insider. Furthermore, integration strategies, as depicted by the clinicians, are devised in the logic of development programs aimed at developing countries. Thus, the representation of Roma as a new version of Gitano patients encompasses the idea of inequality and economic migration. In the next quote from an interview with a nurse, the shared components of the discourse about Roma with other economic migrants are evident:

‘Well, they are asking us (referring to social services) for information about...I do not know, very specific things, such as hygiene, things that I thought that I would never... I thought those were things that we did not need to deal with anymore [...] and we are working on hygiene again, and about healthy dietary habits... the thing is,, well I do not know because it is a little bit weird, quite weird, because we got over those topics and now they are back<sup>66</sup>’

The nurse is referring to the kind of talks that social services ask them to give in one of the multiple programs they have for migrants (migrant Roma among them). The nurse is implying that with Roma, as with some migrants, they need to begin the development process from the beginning to “normalise” them to fit in the national body politic. But migrant Roma bear an extra difficulty, which is their Gitano culture and its alleged unruliness and tendency toward self-marginalization. In one meeting

---

<sup>66</sup> entonces yo creo que es eso sobre todo lo que nos piden y bueno luego ya nos están pidiendo información sobre yo que se... pues más una prevención en algunos casos o con temas muy concretos, higiene, cosas que yo pensé q nunca... que ya no se trabajaban o que no íbamos a trabajar y más en Madrid centro es trabajar el tema de la higiene y estamos volviendo a trabajar el tema de la higiene, estamos volviendo a trabajar el tema de la alimentación alimentación escolar, o sea en críos en el ámbito escolar hablarles de lo que es importante en la alimentación, lo que ocurre es que bueno, no sé, es un poco raro, es un poco raro porque son temas que eran pasados y que estamos volviendo otra vez a vivirlos.

with social services to present new sport activities envisaged for Roma children, the social worker in charge of the project explained the difficulties that the project entailed because of the children's 'cultural specificities' to the audience (mostly NGOs and institutions working with the Roma population). Despite the fact that the purpose of the activity was to play football, the objectives were presented in terms of integration. The representative stated, 'Here we are starting from scratch, so having a shower and getting undressed is a training process<sup>67</sup>'. The notions of development and integration are tightly intertwined.

Last but not least, I consider it important to note that violence or threatening behaviour was not considered a problem related to Gitanos or Roma in the primary healthcare centres where I undertook my fieldwork. Some people mentioned it during the group sessions and individual interviews, and it surfaced in some of their comments, but it was considered to be a problem at the hospital, not at the clinics. Despite the fact that Roma and Gitanos were, to some extent, represented as conflictive patients, at the primary healthcare centre they were not described as aggressive. Nurses and physicians recalling any conflictive encounter with Gitanos expressed how they feared a violence that never took place.

In this section I have sketched the different representations that primary healthcare clinicians hold about Roma and Gitanos. These representations are entangled with institutional logics and organizational mandates and are reinforced or modified by the different practices at the healthcare centre. Different understandings of their professional roles, their duties towards the institution or the patients, the time pressures and their (im)possibility to cope with them; all of these are variables that define the 'repertoire of practices' available at primary healthcare centres. In the next section the analysis moves to the terrain of practice and through three ethnographic vignettes, I investigate the different practices where 'cultural difference' takes multiple forms and meanings.

---

<sup>67</sup> 'aquí si que empezamos de cero, pero ducharse y desnudarse es un proceso de aprendizaje'

## 2. Practices (Encounters)

### 2.1 Cultural (Re)production: Ill-timed Pregnancies

Alba was a 16-year-old pregnant woman. I was there when she went to the healthcare van and her pregnancy test came back positive. When she found out she was pregnant, her happiness made her jump around in the van. Her partner was in a young offenders' detention centre and she could only visit him two or three times per month. She was living with her in-laws and had a passable relationship with her mother-in-law. Despite her young age, she had had another partner before and she had a son from that relationship who was living in Romania with her parents. The baby was born by C-section but she did not know the reason why the C-section had been performed.

During my fieldwork, I tried to accompany Alba to prenatal care, initially in the healthcare van and afterwards at the hospital and the neighbourhood clinic. She was happy to have someone to give her a lift to the hospital and to help her during the consultation because even though her Spanish was quite good (we only spoke in Spanish and we understood each other), she was shy about asking questions during the consultations, as I could see when I accompanied her to the gynaecologist.

Alba did the first trimester blood test at the van and it was not until the second trimester of her pregnancy that she went to the gynaecologist. Alba did not have the means to get out of the settlement and go to the city centre. She depended on someone to either give her the money for the bus or a lift. Even if she had the money, it would be quite difficult for her to find the neighbourhood clinic,<sup>68</sup> so when I offered to go with her she happily accepted. In

---

<sup>68</sup> The neighbourhood clinic location was not a much-frequented place for the people in the settlement. It is quite far from the new neighbourhood and its neuralgic centre –the mall- or the old neighbourhood and its market square, the place where all of the necessary facilities are located (council office, unemployment office, family planning clinic, market, the bus to the hospital). To get to the clinic where the gynaecologist is you need to know the public transport network well. Another difficulty is that the building itself does not look like a healthcare facility: located in the midst of a residential area and dating from the 1990s it is a white building similar in shape and colour to the dozens of apartment buildings that surround it. It is only the small sign next to the main door with the regional public healthcare system logo that identifies the building as a healthcare facility.

my fieldwork diary I noted, “Alba was so happy when I told her I would go with her to the gynaecologist and the ultrasound... I guess I am her only option”.<sup>69</sup>

When the 20-week ultrasound was scheduled, I went to the settlement to pick up Alba and go to the hospital. I was a little bit late and when I got to the settlement Alba was already waiting for me outside her in-laws’ shack. She smiled at me and made a sign with her hand as if she was asking me to wait while she turned to the shack, went into it and came out again with some papers in her hand. When she got in the car, she told me she was already nervous because she thought that I had forgotten about the appointment. After excusing myself for the delay, I asked her if Livia, another girl from the settlement, a friend of Alba’s who was also pregnant, was around. Livia also had an ultrasound scheduled for that same day and I wondered if she could profit from the lift to the hospital. But Livia had already left. Alba told me that her partner had paid an informal taxi to get to the hospital and they had already left. We arrived at the hospital just about on time; when we got into the waiting room they were calling Alba’s appointment number. In the corridor we bumped into Livia and her partner, who were just exiting the same consulting room into which we were heading. Livia’s baby was a boy! Her partner told us this joyfully. Alba smiled at Livia who did not look as happy as the proud father-to-be.

When we went into the consulting room all of the cheerfulness and familiarity disappeared: the gynaecologist, a woman in her fifties, kept on looking at the computer screen when we came in. Only the nursing assistant standing next to the gynaecologist looked at us and invited us to sit down. The gynaecologist was still staring at the clinical records on the screen and she asked Alba the reason why the previous delivery had been a C-section. Alba did not know the answer, and she looked at me as though she were looking for help to answer the question; but I did not have time to reply because the gynaecologist replied herself, “At that age it could have been for anything”. The nursing assistant, Alba and I looked at each other with expectation about what was going to follow, acknowledging the

---

<sup>69</sup> Originally in Spanish in my notes: Alba estaba súper contenta cuando le dije que le acompañaba al ginecólogo y a la eco... creo que soy la única forma que tiene de ir (28/08/2014).

weirdness of the situation where the leading voice seemed to be in a different place (not looking at us at any moment).

The gynaecologist asked Alba why she had not sought prenatal care earlier in the pregnancy. Alba, looking at the gynaecologist- who was still looking at the screen- did not reply and looked back at me as if seeking help. After some seconds of uncomfortable silence, I translated the question for Alba as, had she had gone to the doctor “to see the baby” before? Alba replied no, even though she had previously done blood tests at the van. The gynaecologist scolded her about how important prenatal care was from the beginning of a pregnancy.

After that, the gynaecologist told Alba that she should stop having children after this pregnancy. The antecedent of a C-section or any other medical condition was not mentioned to back up her statement. Instead, she kept on asking Alba: “Do you have a job? And your husband?” Alba replied promptly (finally one question to which she knew the answer) that she did not have a job and nor did her husband, but she told the gynaecologist that they were living with her mother and father in-law and that they provided for the young couple. Still trapped by the clinical records on the screen, the gynaecologist frowned upon Alba’s answer and lectured her about the need to be independent from the grandparents of the baby (“los abuelos tambien tienen que comer”) and stated that she should look for a living to be able to raise her children. She finished her speech by finally moving her gaze from the computer and looking at me. She said, “But these cultural traits are, let’s say, very peculiar”.<sup>70</sup>

The consultation continued and Alba was asked to lie on the examining table in order for the foetus to be examined with the ultrasound. I described this part of the consultation in my field diary as follows:

‘From the computer screen she (the gynaecologist) moves to another one; the ultrasound screen now serves as a mediator for a conversation of a different kind but one as fraught with technical terms as the former. At least, I can perceive a glimpse of empathy while she is showing the baby to the mother (on the screen). Indirectly, the gynaecologist is taking the patient into account and

---

<sup>70</sup> In my field diary, “Son unos usos culturales, digamos, muy especiales”.

tells her about the things that she will be interested in. Straightaway the gynaecologist tells Alba that the foetus was a boy and she shows her the different parts of the foetus' body, the hands, the legs [...] not looking at Alba at any moment but moving the screen towards her so she can see it. Turning the screen to the mother is her way of communicating with Alba. Just before moving to the ultrasound, the gynaecologist told me -or just said aloud to nobody in particular- the previous one was also sixteen'.

After the ultrasound we left the consultation room and Alba exploded in happiness when she told Livia and her partner –who were waiting for us outside the consulting room- that her baby was a boy too. As if the self-containment during the consultation was over, she started smiling again, not in the nervous way she had been smiling before. She was cheerful and happy about knowing the baby was a boy and she shared that happiness with her peers. It seemed that Alba did not mind the gynaecologist patronising and reprimanding her for not being in time for the correct prenatal care. I asked her about the consultation and the attitude of the doctor and she replied by asking me another question: what was the gynaecologist asking her?

(Extract from my field notes)

### **“But these cultural traits are, let’s say, very peculiar”**

This vignette has some methodological connotations that I need to clarify in advance. First, the bulk of my research was in primary healthcare, and my main objective was to analyse “cultural difference” in that context. It seems contradictory or beyond the scope of the research to include an encounter that takes place at the hospital in a specialized milieu. Despite hospitals and primary healthcare centres being part of the same public institution and sharing a similar biomedical framework they are different spaces of socialization. There are two differences relevant for my research: first, hospital workers, despite falling into the category of street level bureaucrats, are not considered frontline workers and they rank higher in medical hierarchies than primary healthcare workers. Secondly, hospitals are usually a place of transit: the temporal framework of longitudinality that organises primary healthcare practices is

not applicable at the hospital<sup>71</sup>. Actually this is one of the reasons why I chose to finally use this “displaced” vignette: I think it offers insight into the provision of care under circumstances where the patient-physician relationship is restricted to the time of the encounter. There were no previous encounters and future ones were not foreseen. Those are the kind of encounters that locum have in primary healthcare when they work for one or two days, but that I was unable to observe for the same time limitations: I did not manage to gain enough acquaintances during their short stays at the primary healthcare centres as to let me be in their consultations. There is a second reason why I chose this vignette and it has to do with my own positionality during the encounter. At the healthcare centre I have observed the encounters mainly from the point of view of the healthcare workers, but in this vignette I observed from the patient’s side without being immediately identified as a healthcare worker, which I think offers a valuable perspective of the encounter. Finally, as I will further argue, teenage pregnancy becomes an important ethnic marker in my research context, as the vignette exemplarily illustrates.

Having clarified these methodological concerns, I would like to begin with the analysis of the process of identification during the encounter. One of the first things that struck me during my accompaniments to prenatal care was the lack of eye contact that clinicians had with patients. The scene depicted in the ethnographic vignette, with a clinician staring at the computer screen and not even looking at the patient was a constant in the prenatal care encounters I observed. It seemed that all the relevant information was already sorted out in the clinical records and the presence of the patient was not necessary until her body was to be subjected to new scrutiny to obtain more data to complete the clinical records. Alba’s example illustrates a kind of clinical practice that is basically grounded in standardized care: the clinician closely follows the prenatal care protocol as a means of providing quality healthcare, a kind of healthcare provision that is not exclusive to Gitana patients. Still, in Alba’s case, providing standardized care did not stop the physician from sharing her moral judgements about Alba’s reproductive decisions. Moreover, the physician identified Alba ethnically through the demographic and standard physical facts noted

---

<sup>71</sup> There are some conditions that may require a specialized continuity in care provided at the hospital, but longitudinality is not a core principle that organizes hospital practices.



down in the clinical records: being sixteen and having her second pregnancy, with a previous C-section, was enough to identify the patient as Gitana (or Romni). In this case, the standard biological facts are loaded with values that ethnically identify the patient and stigmatize her, inasmuch as ‘teenage pregnancy’ is socially constructed as a problem.

I will further develop the connection between teenage pregnancy and Gitanos/Roma in the subsequent section but first I would like to explore how care was provided in this encounter. Timmermans and Berg, in their historical analysis of evidence-based medicine, note how ‘clinical practice guidelines embody the extent of medicine’s jurisdiction’ (2003, 83). In Alba’s case, it seems that despite the gynaecologist identifying the patient as Gitana through the demographic data, there was a subsequent separation of this data from the provision of care. As I noted in my field diary, I was surprised (ever angry) that the gynaecologist recommended Alba not have any more children but she did not base her advice on what she considers is biomedical but on social grounds: for the gynaecologist the main concern was avoiding the reproduction of a mistaken social pattern and not the effect of a new pregnancy on Alba’s health. In doing so, the gynaecologist clearly separated what is social (and therefore outside of her clinical realm) and what is biological (the reason for her practice). My argument is that this separation of the standardized biological facts from the biographical patient’s values marks the limits of what is considered to pertain to biomedical practices and therefore, what is considered to be good practice. As the biographical data represents a transgression of the social norm, it is discarded as a “peculiar cultural trait” while the focus of the encounter continues in the standardized biomedical guideline.

In her book ‘The Logic of Care: Health and The Problem of Patient’s Choice’, Annemarie Mol (2008) compares the logic of choice and care in clinical settings and the practices in which these logics are embedded. Mol describes practices based on choice like those where clinicians are the managers of scientific knowledge, which is understood as a growing collection of facts that gradually increases in certainty. Clinicians are supposed to manage this information and give it to the patient, who makes choices in accordance with her values (2008). Mol stresses the idea that in the logic of choice, those that are considered “normative biomedical facts” are differentiated from the patient’s values and not affected by them. Clinical guidelines

and protocols are part and parcel of the logic of choice: biomedically relevant facts are gathered together to represent the patient in a standardized manner and propose a subsequent set of actions guided by clinical guidelines. Healthcare provision based on protocols and clinical guidelines is considered synonym of “good practice” in clinical arenas. As Timmermans and Berg argue,

‘the medical profession has benefited greatly from the uniformity [...] Standards have been explicitly used to rid medicines of quacks, impostors, and alternative forms of healing and to put the human body under the jurisdiction of physician, nurses and other officially sanctioned medical groups’ (2003, 83).

In the encounter between Alba and the gynaecologist, the authoritative knowledge over the body that biomedicine and its protocols awards to clinicians went beyond the boundary of the physical to judge the biographical while excluding the biographical from the provision of care. There are no references to Alba’s motherhood aspirations or what the pregnancy means for her. The gynaecologist perceives the possibility that Alba might desire to be pregnant at her age as an incongruity, and therefore the gynaecologist categorizes it as “cultural difference”. Following Mol’s reasoning, in this case Alba’s values are detached from her biological facts, but this detachment does not leave the biological “facts” free of values, since the gynaecologist ascribes her own: for her, teenage pregnancy is a social transgression and in this case it is due to cultural peculiarities. Besides, the values ascribed to Alba’s pregnancy not only differentiate her culturally, but also reflect on the social evils that teenage pregnancy entails: instead of striving to become an autonomous and active citizen, Alba (and her partner) are reproducing a system of dependency on others (their parents in this case) and apathy in taking care of themselves by not having more children.

The way the gynaecologist addressed Alba’s unacceptable deviation from the social norm (her desire to be pregnant at sixteen) is: first, by using it to identify Alba ethnically to subsequently judge her behaviour as socially illegitimate inasmuch as it encourages her dependency on others. Finally, once the wider social values have been ascribed to Alba’s biological facts, the gynaecologist continued the consultation in the standardized manner, following the clinical guideline. It was only at the examining table, and mediated through the foetus’ image on the ultrasound screen, when the clinician talks to Alba directly, showing her the images and providing information about the foetus that the gynaecologist thinks Alba would like to know (because she

did not ask her at any point). As with any other pregnant woman, while ignoring the patient's age, the physician did a routine check to detect any anomaly in the foetus, and shared it with Alba. For quality evaluations, we could say that the provision of care in Alba's case was adequate, as the guidelines were followed and the scheduled ultrasound was performed.

For the gynaecologist, the principle that grounds this kind of standardized practice is the idea of egalitarianism, understood as performing similar procedures independently of the patients' differences. However, as I have already shown in the admission desk chapter, this idea of egalitarianism entails the risk of glossing over important differences that need to be taken into account when providing adequate healthcare. For instance, in Alba's case, there were reasons from a biomedical point of view to recommend that Alba space apart her pregnancies, as she had a previous C-section, but this biological fact was not highlighted during the encounter. Actually, the fact that there could be some complications due to this medical antecedent was not mentioned or foreseen. The temporal framework that the gynaecologist uses just foresees the near future: despite her insistence on the need to take preventative measures (prenatal care) it seems that the consequences for Alba's health of this or new pregnancies are neither explained to Alba nor given any attention during the encounter. This counter-intuitive gynaecologist's approach to preventative measures is in relation to two things: first, the gynaecologist is only accountable for correctly performing the prenatal care task that she is in charge of (the ultrasound). As she does not have any other therapeutic tie to Alba, the gynaecologist focuses on the present pregnancy and does not set it in a wider temporal framework. Secondly, teenage pregnancy is fraught with tensions that the gynaecologist ultimately translates into cultural difference. It is when teenage pregnancy is ethnicized as a salient Gitano feature that the negative stereotypes about Gitanos appear and delegitimise inasmuch as they are perceived as a lost cause.

Alba's encounter with the gynaecologist is a good example of how the stereotypes work as a protocol in consulting rooms: at the admission desk it was the gathering of some features that prompted this kind of identification whereas in the consulting room it is standardized clinical facts that allow for identifying the patient as Gitana without looking at her. By means of standardized practices, which were conceived to reduce inequalities in the provision of care, the patient is ethnically identified and

subsequently delegitimized. When teenage pregnancy becomes an ethnic marker and is depicted as a cultural trait that causes Gitanos and Roma to deviate from social normalcy, it is no longer a matter of clinical practice. Neither are Alba's views about her pregnancy a matter of concern for the clinician: as Alba is not considered an active and autonomous citizen, her right to choose is not even contemplated during the consultation. Again, the enactment of the logic of choice does not entail the participation of the patient or her possibility to choose. Instead, she remains alien to the clinician's concerns and focuses on fulfilling the expectations she has deposited in that encounter: to learn the baby's sex.

### **Cultural pregnancies**

Personal and state projects are entangled in the field of reproductive health (Fassin 2011b; Murphy 2012). Michelle Murphy signals this entanglement:

‘Reproduction was not a biological thing with clear bounds, but a multifaceted and distributed effect in time and space, a problem both material and political to which questions of state, race, freedom, individuality, and economic prosperity were bound in ways that connected the micrological with the transnational via embodiment’ (2012, 6).

Likewise, Fassin (2011b) reminds us that different family planning programs are the enactment of diverse forms of governance –which can be liberal or authoritarian- but nevertheless are shaped by a normalizing biopower. The ethnographic example from the gynaecologist's consulting room shows how reproductive health exceeds the biological realm: first by ethnicising a reproductive pattern (teenage pregnancy) and secondly by enacting a form of biopolitics that problematizes these pregnancies as troublesome and, to some extent, socially illegitimate.

A young age at the first pregnancy and high fertility rates, in the eyes of healthcare workers, represent a sign of the unruliness of Roma and Gitanos. The perception that the healthcare workers had of Gitanos' and Roma's reproductive patterns was homogenised as a shared cultural trait that entails having the wrong number of children and doing so far too early. Thus, the desire for motherhood at a young age serves both to mark a cultural difference based on ethnicity and what is considered the social self-exclusion process of Gitanos and Roma. According to Jane Schneider and Peter Schneider (1996), who studied population decline in Europe, the politics of

reproductive stigma originated in the late nineteenth century when a declining birth rate began to be associated with normative Western middle classes. In their words, the ‘historical experience of limiting family size through sexual discipline – and in a context of social hierarchy – left behind a cultural residue that makes it easy to attribute any number of social ills such as backwardness, underdevelopment, and poverty to reproductive practices that elude consciousness or “rational control”’(Schneider and Schneider 1996, 13).

Faye Ginsburg and Rayna Rapp refer to “stratified reproduction” to analyse these ‘arrangements by which some reproductive futures are valued while others are despised’ (1995, 3). In this case, Roma and Gitanos’ pregnancies are undervalued inasmuch as they are associated with teenage pregnancy. Pregnancy at an early age not only speaks of erroneous timing, but also of reproducing a set of cultural traits that are not in accordance with prevailing ideas of progress and modernity. In the case of Gitanos and Romani in this context, their reproductive behaviour –mainly because they are “too young”- digresses from prevailing reproductive behaviour and, to some extent, serves to confirm the insurmountable differences between Gitano culture and wider Spanish society.

The importance assigned to teenage pregnancy amongst Gitano populations transcends the focus of this research. There are several examples showing how pervasive the connection between ethnicity and teenage pregnancy is in Spanish medical journal articles in regard to Gitanos’ health. For example, in an article about the attitudes of teenage Gitanos to drug use and sexual behaviour the researchers state: ‘The Roma are characterized by high fertility rates and very early pregnancies’<sup>72</sup> (Garcia de Cortazar et al. 2009, 606).<sup>73</sup> Similarly, in another article

---

<sup>72</sup> In this article they refer to Gitanos but translate it in English as Roma

<sup>73</sup> This journal article -published in an international journal specializing in qualitative health research- follows a particular reasoning: throughout the whole article there is a description of the findings of their research, which is always interpreted with an ethnic lens. They describe how Gitano teenagers smoke (or do not), have risky sexual behaviours (or do not), and so on, while describing what the authors consider ‘Roma characteristics’. What is striking is the last paragraph of the article: after the long and detailed ethnic description, the authors state that there are no significant differences between the Roma and non-Roma teenagers with whom they conducted the research (Garcia de Cortazar et al. 2009:617).

about the evaluation of the primary healthcare prenatal care programme, the authors suggest that the higher rate of teenage pregnancy in their sample is due to the presence of a marginal area with a high rate of Gitanos:

‘In our data it is relevant to notice the far from negligible number of inhabitants of the Gitano race in the ZM (stands for “zona marginal” marginal area). This fact may explain, at least partly, the high rate of teenage pregnancies in this area, due to the idiosyncrasy of this ethnic group that tends to *accept and even desire pregnancies at very early ages*’<sup>74</sup> (Mitsuf Gallardo et al. 1997, 192 emphasis mine, my translation).

Similarly to the physicians and nurses I interviewed, the authors of these journal articles connect Gitanos both to marginal settlements and teenage pregnancy and subsequently make a judgement about the inadequacy of that kind of reproductive behaviour. In the clinical milieu, either in journal articles or healthcare facilities, teenage pregnancy is presented as something to avoid: the deviance that *desiring* to be pregnant during adolescence represents is explained in cultural terms. Adolescence is not the right time to be pregnant and therefore, following the reasoning behind public health prevention and health promotion, this is a situation that deserves an intervention program in order to reduce the number of teenage pregnancies:

‘These results should make us reflect on the need for intervention of the teenage population, especially in the ZM (marginal area). It would be advisable to attract the largest possible number of teenagers to the family planning program and to introduce a specific pregnancy protocol for teenagers’<sup>75</sup> (Mitsuf Gallardo et al. 1997, 193 emphasis mine, my translation).

In the same journal article, they explain how most of the pregnant teenagers they encountered in their research came from the marginal area of the neighbourhood. Despite the fact that they contrast this data with other studies that show that being

---

<sup>74</sup> “En nuestros datos es relevante señalar el no desdeñable número de habitantes de raza gitana en la ZM, que podría justificar, al menos en parte, el elevado número de embarazos en adolescentes en esta zona, debido a la idiosincrasia de esta etnia, que tiende a aceptar e incluso desear gestaciones en edades muy tempranas.”

<sup>75</sup> Estos resultados deben hacernos reflexionar sobre la necesidad de intervención en la población adolescente, sobre todo en la ZM. Sería recomendable captar el mayor número posible de adolescentes para el programa de planificación familiar e introducir un protocolo de atención específica en adolescentes

illiterate and having a low socio-economic status are correlated with teenage pregnancy, the authors insist on signalling the ethnic background of the inhabitants of the marginal area. Likewise, little is said in the article about the possibility of having included pregnant Gitanas from areas other than the marginal one in their study, and there is no information about the age at which they have their first child. This journal article seems to suggest that all Gitanos live in marginal conditions and all of them have children at a young age.

In the article and for most of the healthcare workers I interviewed, low socioeconomic conditions and marginality are entangled with Gitano culture in the presentation of teenage pregnancy as a cultural phenomenon that needs to be corrected. This entanglement reflects on the double 'ill-timing' of Gitanos culture: On the one hand Gitano culture is perceived as being accountable for the wrong timing of pregnancies; on the other hand, this erroneous reproductive timing is presented as accountable for their lower socioeconomic status and for thwarting their opportunities to climb the social ladder, leaving Gitanos on the fringes of developed and modern Spain. For these physicians and nurses, teenage pregnancy signals Gitanos' and Roma's backwardness and the need for special development programmes to reduce their old-fashioned tendency to have more children than average Spaniards and at a younger age. Gitano culture provokes this wrong biographical timing, which is both the cause and result of a lack of development.

The ethnographic vignette is representative of one of the main topics regarding Gitano cultural difference that appeared during the interviews and at the clinical encounters. The conflict between the moral values taken for granted in regard to adequate biographical timing and adequate conditions for procreation, endorsed in clinical contexts, and those of some Gitanos is crucial to understanding the representations of Roma and Gitanos. One of the common points in most of the interviews with the nurses and physicians was the fact that they found it difficult to understand and give medical advice to pregnant teenage Gitanas. The association between being Gitana and teenage pregnancy was taken for granted in both healthcare centres, and the absence of teenage pregnancies was considered a degree of progress in terms of the inclusion of the Gitano family in mainstream society. For the physicians and nurses, the fact that a Gitana had her first child in her late twenties was proof of her successful integration whereas having children at an earlier age

functioned as a marker of suspicious otherness. Delaying pregnancy was interpreted as a step forward towards abandoning the backwardness of Roma and Gitano culture.

Teenage pregnancy is a digression from social norms, which are generally taken for granted by healthcare professionals. Therefore, in biomedical settings, physicians and nurses problematize teenage pregnancy as a failure, both social and institutional.

From an institutional perspective, teenage pregnancy is a failure because it is understood to be the result of the unavailability and inadequacy of contraceptive medical services for teenagers. On the other hand, teenage pregnancy is perceived as a social failure because it is the result of parental disregard, and in some cases, even negligence. The problematization of teenage pregnancy as a failure points to what Shellee Colen (1995) have dubbed ‘stratified reproduction’; having children during adolescence is censored as a social evil whereas there is no legal age limit for IVF (in vitro fertilization) in the same context.<sup>76</sup>

Some doctors and nurses also commented on the sense of wrongness they have when giving advice about fertility techniques to teenagers. One resident nurse, during an informal coffee break, when asked about her experience in the healthcare van, told me: ‘I was so shocked when I heard you giving advice to a 16-year-old girl about how to get pregnant, when what we should do is explain to her how not to get pregnant [...] that is one of the things that struck me most about the consultation at the van’. Teenage pregnancy questions the limits of care and advice for nurses and physicians while delimiting the boundary between their role as a “normalising” institution (in Foucault’s sense) and that of caring for their patients and respecting diversity. The ethical dilemma –confessed in emotional terms during the coffee break - of the resident nurse shows the deep roots that the problematization of teenage pregnancy as a failure has.

The next quote from an interview with a GP expresses the kind of contradiction that doctors and nurses feel when attending teenage pregnancy:

---

<sup>76</sup> Differently from other countries in Europe, in Spain there is no legal age limit to go through assisted reproduction treatment, provided that patients are eighteen or older.



Before, I had promoted protection against teenage pregnancy; we have taught courses at the local secondary school to promote sexual and emotional health, a consultation for teenagers [...] everything to encourage them not to get pregnant during adolescence, then [...] when I arrived here and saw that here, when they are fifteen – and that was part of the first shock when I moved to this centre- they told me that they have been trying [...] that they do not get pregnant [...] they asked me for some treatment to make them get pregnant. 15-YEAR-OLD GIRLS WITH TWO CHILDREN!!! My goodness! Then, well, I had to change my mindset, I mean, I have spent fifteen years of my career promoting protection against teenage pregnancy, promoting teenagers' access to at least the information, that at every moment they could be protected and they could come to the healthcare centre without telling their parents if there had been a slip-up, but here it was the opposite. Moreover, I had some cases of young couples of Gitanos with three children [...] when they get pregnant the fourth time and they want an abortion, finally they have the baby because of the family's control [...] who does not allow them to have an abortion. And they are 20 years old, and the family does not accept the abortion, so despite being 22 years old and not wanting the fourth, they can't do it (have the abortion) because of the family's surveillance, the clan's...'<sup>77</sup>

So far, in clinical settings, the difficulties of grappling with the social digression that teenage pregnancy represents, be it the obstetrician's office or the primary care clinic, are evident. Alba's biographical account, with her previous C-section and her current pregnancy, triggered a reaction from the gynaecologist, who, instead of integrating this information with the physical exploration, shared her disapproval with Alba. But

---

<sup>77</sup> Luego, la actuación con ellos es muy diferente , muy muy muy diferente porque yo al principio venía de una zona donde promovimos la protección frente al embarazo en adolescentes, creamos cursos en los institutos de educación para la salud, afectivo sexual, consulta joven, todo para promover el que no se quedaran embarazadas en la adolescencia, entonces cuando llego aquí me encuentro que con 15 años , uno de los shocks primeros, me decían que llevaban... que no se quedaban embarazadas, que les diese algo para quedarse embarazadas. NIÑAS DE 15 AÑOS CON 2 HIJOS , dios mio!!!! Entonces, claro, he tenido que cambiar las ideas, quiero decir, yo me he pasado 15 años de mi vida promoviendo que no haya embarazos en adolescentes, que puedan tener, o sea un acceso a,,, por lo menos información, que estuviesen en cualquier momento protegidas que si tienen un pequeño fallo pudieran venir corriendo al medico sin q los padres lo supieran, pero aquí lo contrario, pero encima (énfasis) en algunos casos que me he encontrado de parejas gitanas jóvenes con 3 hijos se quedan embarazadas por cuarta vez, deciden abortar y al final no lo hacen porque les tienen vigilados la familia y no les dejan por la familia. Porque como viven con los padres no podían escaparse y que los demás lo supieran, y ahí tienen al cuarto. Y tienen veinte. La familia no acepta el aborto, entonces aunque tienen 22 y no quieren el cuarto no pueden hacerlo por el control de la familia, del clan...

this disapproval, expressed in those terms, had little to do with Alba's prenatal care needs (even when defining prenatal care in the strictest biomedical sense). Returning to the vignette, the encounter was split into two parts: the opening part with the conversational review of her medical history that was analysed previously, and the second part when the clinical exploration and the ultrasound took place. This separation of the psycho-social (the patient's narrative) from the biological (in this case the ultrasound exploration) is the *modus operandi* in physicians' and nurses' consultations, to finally combine both in the final part of the consultation. But interestingly, at the gynaecologist's office, this division reflects upon the differentiation between the biographical and the physical: while the former became a source of disagreement that prompted an identification based on stereotypes, the latter remained in the realm of objectivity and neutrality. Still, not every "biomedical disagreement" ends up in an identification based on stereotypes; next vignette will show that some biographies are better tolerated than others.

## 2.2 "You Are More Modern than the People of Tomorrow"<sup>78</sup>

At the "multicultural" neighbourhood healthcare centre, most of the physicians and nurses called me when they had a Gitano or Gitana patient. One afternoon, Lucia, a physician, called the consulting room I was in and told me, "I have Azucena on my list and I saw her in the waiting room, she is waiting there. Do you want to come to the consultation and talk to her?" I agreed and after excusing myself to the patient and physician I was with I headed to the waiting room. In front of Lucia's consulting room door there were four people sitting and waiting, three women and a man. Three of them were chatting in a lively way. At first sight I had no clue which of them could be Azucena; actually I wrote in my field notes, "I thought she was gone or already in the consulting room, but when Lucia came out and told one of the women who was chatting to come in, she motioned me into her office and I understood that this woman was the Gitana patient".

The consultation was full of mutual understandings between a physician and a patient that had known each other for a long time. Lucia took advantage of my presence to remark on some health

---

<sup>78</sup> "*sois más modernas que las de mañana*"

issues that, in her professional opinion, Azucena should take care of. Lucia explained to me -with a nodding Azucena next to her corroborating the physician's words- that Azucena was taking care of her husband who was blind and dependent on her, and that that was the reason why she did not want to have a much-needed operation. Actually, that afternoon her husband had an appointment to get new prescriptions but, as she had twisted her ankle three days before and the pain was getting worse and worse, she had decided to schedule an appointment for herself too. While Lucia diligently removed the bandage that Azucena's neighbour has put on her ankle, she insisted on the idea that Azucena should take care of herself in order to be able to take care of her husband: "When you can arrange things with your husband, tell me and I will send you to the surgeon". Afterwards, Lucia meticulously examined Azucena's bare ankle and referred Azucena to the treatment room to get a new dressing.

I accompanied Azucena to the treatment room and waited with her until the nurse called her in. We chatted about her husband's disease and her family life and when we entered we shared a little bit of our conversation with the nurse, who also seemed to know Azucena from before. While the nurse was placing the bandage on the injured ankle, Azucena tried to justify herself, saying that she had always been very committed to her husband. She burst into tears while telling us how difficult it was for her to see him like that, and how she avoided telling her children about any of her concerns. The nurse minimized the dramatic effect of the crying and told Azucena that she was very nice with her husband, that she knew that she was one of those women who was "*chapada a la antigua*" (old-fashioned), always taking care of her husband and of everybody. Azucena, still with tears in her eyes but with a smile on her face, told us that that was the only way she knew how to be. The nurse started to kindly tease Azucena about how "they were" (she used the plural instead of referring just to Azucena)<sup>79</sup> when taking care of "their husbands". The nurse made a correlation between being as traditional in a feminine role as Azucena was and working in antiquities shops, as if being "*chapada a la antigua*" was a professional deviance due to dealing with antiques. Azucena laughed and agreed with the nurse, saying that the women from her generation were as

---

<sup>79</sup> (women like her, not explicitly saying Gitanas, but implying it)

old as the old things they sell in the shops, but she added that the new generations were very different and had different values. She said that at the Pentecostal church you could see how modern the young women were. The nurse laughed and said, “Yes, you are more modern than the people of tomorrow”.

This extract from my fieldwork diary illustrates a Gitana-physician encounter that is substantially different from the previously described encounter with the gynaecologist. In the latter vignette, the gynaecologist used stereotypes as protocol in relation to a reproductive behaviour that diverged too much from what is considered acceptable in clinical settings; a norm that nevertheless derives from values ascribed to teenage pregnancy in the wider society. The difficulties in that encounter came from the enmeshment of societal norms with biomedical knowledge and the limits between what is considered social and what is considered biomedical.

In the former vignette, Azucena’s behaviour- despite its diversion from the “biomedical norm” due to her refusal to undergo surgery- does not set in motion the use of stereotypes as protocol. Actually, neither Lucia nor the nurse openly mentioned “culture” to explain Azucena’s refusal to follow medical advice. Instead of using ‘culturalism as ideology’ (Fassin 2001) Lucia and the nurse blurred the symbolic boundaries between Roma and non-Roma culture, accommodating Azucena’s digression into the cultural representation of the female caregiver role. Being Gitana is one of many reasons that influence the patient’s decision but not the decisive one; the figure of the female caregiver is available to frame Azucena’s behaviour as non-divergent from the social norm. Therefore, Azucena transgressed the biomedical mandate (by not undergoing surgery) but she did not diverge from the social norm.

In Azucena and Lucia’s encounter, there were some necessary, but not sufficient, conditions to facilitate that kind of encounter. First, the identification of Azucena as Gitana does not come from a stereotypical representation of Gitanos: no mention was made of the ‘urgent’ appointment she made, just because she had to go to collect her husband’s prescription anyway, nor to the fact that she was talking outside with three other people, which could lead us to think that they had come to the healthcare centre together. Actually, I could not identify who Azucena was until the physician called her and signalled to me. Therefore, the identification of the patient as Gitana was not based on ascribing Azucena with negative representations of Roma and

Gitanos. The identification as Gitana was based on the relationship established over time between her and the healthcare workers. For this identification to be possible, one of the necessary conditions is longitudinality.

‘Longitudinality’ is the term Barbara Starfield (1998) coined to refer to the continuity of care in primary healthcare and the relationship established between patients and professionals over time. As in the admission desk workers’ vignettes, in this vignette the identification is based on acquaintance, and it signals the degree of closeness of the physician-patient relationship. This acquaintance needs time and consecutive visits to develop, as well as a certain predisposition to taking the patient’s decisions as crucial when designing her “therapeutic plan”. Time becomes important in these clinical encounters not just because of the availability of appointments (having time to attend to the patient), but also for the establishment of the patient-physician relationship over time (becoming a regular source of care for the patient). Both Lucia and the nurse knew Azucena from before; they knew her husband, and the difficulties regarding involving their children in their father’s care. They had established a relationship over time because Lucia was Azucena’s *‘médica de cabecera’*: she had gone on house-calls to Azucena and her husband every time she needed to for a number of years, the time Lucia had been working at that healthcare centre. It is because of this relationship over time that Lucia and the nurse identified Azucena as Gitana.

Even though longitudinality is praised as one of the pillars of primary healthcare, it has been threatened during recent years by the austerity measures deployed by Madrid’s regional governments. The number of temporary contracts has increased and the delay in public exams to gain a permanent position has created a pool of mobile physicians and nurses working as locums for very short periods, sometimes just for one or a few days at a time in different healthcare centres. If one of these locums had consulted Azucena on that day, she would have just had to take care of her twisted ankle, but probably he or she would not have advised Azucena about the needed surgery, as she would not be aware of Azucena’s circumstances. With a locum physician or nurse, the care Azucena might have received would have been focused on the acute problem that brought her to the healthcare centre, which was isolated from the rest of her circumstances.

Furthermore, identification through acquaintance involves time beyond the current consultation, and if establishing that relationship over time is not possible, it is difficult to identify Roma or Gitanos as such unless it is through negative stereotypes. I could not identify Azucena as Gitana in the waiting room, even though I was told that she was waiting there. Azucena is one of those Gitanas who does not match the negative stereotype, and therefore her identification as Gitana remains invisible to those who just treat her once or twice. Longitudinality allows for identification based on acquaintance, and if it is curtailed, positive identification of Roma and Gitanos is curtailed too.

Secondly, it is interesting to analyse the way in which Lucia, the physician, carried out the consultation. Knowing beforehand that Azucena had twisted her ankle (the administrative clerk wrote it down in Lucia's electronic agenda) Lucia directly addressed that problem: while listening to the story about how Azucena fell and how afterwards she sought help from a neighbour, Lucia fetched a stool to put Azucena's leg on. Then, she brought up her concern about the surgery that Azucena was postponing while removing the bandage from the injured ankle. The conversation moved from Azucena's injured body to her biography: the relationship with her husband, all of the difficulties they have been through since he went blind, and how she was devoted to him full-time. Lucia schematically presented this biographical account, partially to include me in the conversation and partially because she could benefit from my presence to show Azucena that she was aware of the difficulties but still advised her to undergo surgery. Lucia engaged in caring for the injured ankle and moved beyond that specific problem to situate it in the wider context of Azucena's life. The body is embedded in the biography and the physical exploration is not dissociated from the conversation: the acute problem is enmeshed in the previous problems and the physician uses it to strive for future solutions.<sup>80</sup> This kind of approach – where the physical is embedded in the biographical- is another condition that facilitates the identification of Gitanos and Roma through acquaintance.

---

<sup>80</sup> One interesting aspect of this encounter is that there was not the usual spatial division between the clinical interview (at the desk, in the front area of the office) and the physical explorations (at the back of the office, behind the curtain).

The encounter between Lucia and Azucena was characterised by the blend of Azucena's consulting concern (the twisted ankle) with Lucia's biomedical concern (the surgery). These were different concerns that provoked neither a conflict nor a cultural explanation of this difference. Instead of presenting Azucena to me either as a non-compliant patient or as driven by the "typical fatalism" of Gitano culture, Lucia explained the rationale behind Azucena's decision to postpone surgery. Lucia insisted on the convenience of early surgery while respecting and moulding her advice to Azucena's needs. Furthermore, Gitano culture was not elicited to explain Azucena's decision, although she was not following the advice. Moreover, Lucia could have just limited her intervention to taking care of the twisted ankle, as she knew of Azucena's refusal to undergo surgery. Nevertheless, Lucia brought up the topic because in her view it was something important for her patient's health and she should help her decide what was best for her.

So far, longitudinality and the "biographical approach" appear to be the conditions of possibility where identification based on acquaintance takes place. But in this case, there is another interesting point to investigate: the link established between traditional female roles as caregiver and Gitanas. Inasmuch as the representation of Gitanas as caregivers does not digress from the representations of the traditional feminine role the ethnic identification of Gitanas is blurred into the representation of women as caregivers in the broader social and historical context. This representation of the traditional female role in the shared social imagination downplays the identification of Azucena as Gitana and instead highlights how she has been brought up in a specific historical period. This caregiver role is praised and disregarded at the same time: on the one hand, there is professional recognition of the role of informal caregivers and their work, which is barely recognised in other contexts. On the other hand, the dependence and submission of wives to their husbands is criticised for being a backward moral value that perpetuates patriarchy and consequently obstructs gender equality. Nevertheless, the embodiment of these traditional feminine values, such as caregiver, submissive and home-oriented is not perceived as a social digression and is, to some extent, a sign of the degree of backwardness.

Azucena's medical digression was understandable to the physician and nurse because it is coherent with the values and expectations that a woman of her age lives up to. Women brought up during the Francoist regime under very restrictive gender models

needed to be submissive to their husbands and their activities were restricted to the household and to taking care of the children and their husbands. Therefore, this gender model was not specific to Gitanos and -as Azucena's example shows- there are continuities between the Gitanos' and non-Gitanos' gender identities, which helps to downplay Gitano stereotypes. Paloma Gay y Blasco (1999) also noticed the continuities of Spanish and Gitano gender morality models in her research with Gitanos from Jarana. Gay y Blasco argues that the importance conferred to female virginity before marriage among the Gitanos of Jarana has to be understood in the wider Spanish socio-cultural context, and that their emphasis on female chastity is part of a wider Spanish one (1999, 90).

In my research context, women adopting caregiver roles is taken for granted, although there are other competing models of feminine roles. Besides, these gender asymmetries affect women physicians, too. Teresa Ortiz Gómez's (2005) historical research on the professional identities of women physicians during the Francoist regime shows how these women developed their professional role as assistants to their husbands (who were physicians, too) while taking care of the household chores and their children's upbringing. Ortiz Gómez states 'the Spanish woman physician of the sixties –the period when women started participating in Spanish medicine- assumed the patriarchal discourse and practices of her time as a means, or as a strategy, of professional integration' (2005, 96).

Other research has shown that women physicians are overrepresented in positions that allow them to combine professional and family life (Brooks 1998) or in specialities pertaining to child and elderly care (Riska 2001). In the Spanish context, Lorena Saletti Cuesta (2015) conducted research among general practitioners in Andalusia. Discourse analysis shows that most female general practitioners did not plan for professional goals and in case of planning, the professional goals were intertwined with family needs, a intertwinement that points to persistent gender differences in professional contexts and in broader Spanish society.

Delgado Sánchez, Távora Rivero, and Ortiz Gómez (2003) identify that young women physicians have a conflict between their identity as professionals and their identity as women. They signal how this conflict hints at the boundaries between the professional and the gender role:



‘The women physicians in our research believed that psycho-social care- care based predominantly on the patient’s experiences rather than the physical symptoms of disease- is something instinctive and typically feminine that they are not clear about, or do not assume that that kind of care constitutes a work method and is therefore technical. This confusion shows the ambivalence present in research groups between “being better” as a professional and “caring better” as a woman’ (2003, 598 my translation).

This research shows how gender differences persist in Spanish society and how these differences linger in professional healthcare contexts too. Although it is true that there have been changes in the discourse from the submissive role (working as their husband’s assistant) of the first woman physicians to young female general practitioners, who nevertheless question their professional role as not being professional enough, these changes are framed in the logic of progress and modernity according to which women who adopt traditional roles are perceived as old-fashioned. For elderly women, this backwardness is excused mainly because of their upbringing during the Francoist regime, while in younger women this traditional role tends to be contested.

That the traditional feminine role is perceived as old-fashioned is evident in the conversation between the nurse and Azucena in the consulting room. Moreover, the nurse subtly connects Azucena “old-fashioned” gender role with Gitanoness, when joking about being traditional and dealing with antiques, as if her gender role derived from her occupation (or vice versa). When the nurse joked about the professional deviance of being traditional because the family sold antiquities, she did so because she knew that there were a lot of Gitanos in the neighbourhood who were antiques dealers.

It was Azucena who pointed out the generational changes in gender roles among Gitanas: following the logic of progress and modernity Azucena stated that young Gitanas are ‘very modern’. But the nurse questioned those changes and showed her disbelief by joking: ‘you are more modern than the people of tomorrow’. Drawing from the stereotype that depict Gitano culture as backwards, the nurse was questioning that there were Gitanas who embrace other gender models than the traditional one. Despite Azucena not being identified as Gitana based on negative stereotypes, the representation of Gitanos and Roma as backwards seeped into the nurse jokes. Azucena embodies a gender role that is ill-timed for “modern” Spanish

society but nevertheless her deviance is no different from other Spanish women of her generation, enabling a generational identification that downplays cultural difference. Still, the social representation of Gitanos as backwards –and in that sense ill-timed for the present time - subtly appeared in the encounter with the nurse.

### **2.3 ‘They See Diseases When There Are no Such Diseases and They Don’t See Them When They Suffer From Them’**

So far I have conveyed how Gitanas and Romani are problematized as deviant subjects because of their fertility patterns, which are explained only in ethnic and cultural terms. Secondly, I have analysed how even though some so-called ‘Gitano cultural traits’ are more acceptable (the example of the wife taking care of her husband), Gitanas are still depicted as backward women who need specific programmes to catch up with modern non-Roma women. This analysis has focused until now on the relationship of Gitanas with nurses and physicians, and this relationship basically revolves around representations of women as mothers or caregivers. To include Gitanos in the analysis, I am going to move on to another topic that is directly linked to them in the biomedical reasoning of nurses and physicians: cardiovascular risk and the conundrum of lifestyles, genetic risk and social determinants of health. This focus on Gitanos does not mean that the same kind of stereotype is not applicable to Gitanas; we will see that most of the framing about the lack of prevention is similar for both men and women. Men are the targets of preventative cardiovascular measures on the basis of higher prevalence of risk behaviours, such as alcohol and tobacco consumption (MSSSI 2016). Women are the target of preventative gynaecological measures although there is no evidence that there is a higher prevalence of gynaecological diseases among Gitanas and Romani.<sup>81</sup>

---

<sup>81</sup> The focus on gynaecological prevention programmes for Romani and Gitanas is present in all of the policy and technical documents that tackle the health of the Roma population. See for example the document from the Ministry of Health providing the debriefing of the national health survey of the Roma population (entitled “Towards Equity in Health: closing the gap in a generation in the Roma community). When talking about preventive healthcare programs, the main priority is: ‘to foster the preventive function of primary health care services, taking into account that they should be oriented towards the community and that active recruitment should be used when necessary. In a parallel way, to improve the level of assistance in gynaecological consultations in Roma women of all age ranges to reduce inequalities in access to this service as a form of increasing preventive practices’.

The title of this section is a verbatim taken from one of the group sessions I organized at the primary healthcare centres. One of the physicians expressed her difficulties in consultations with Gitanos as being due to a problem of misunderstanding: *‘They see diseases when there are no such diseases and they don’t see them when they suffer from them’* (woman, November 2013). What this physician implied is that Gitanos do not properly embrace the biomedical model of health and disease, and therefore they are mistaken in their interpretation of their bodies. In that sense, the representation of Gitanos encompasses the notion of ‘unsanitary citizens’ (Briggs and Mantini-Briggs 2003), as they are represented as people who, either because they are not able to or because they do not want to, do not interiorize the biomedical understanding of the body.

This statement about the wrongness of Gitanos in their understanding of their bodies also resonates with the notion of “hyperchondriac” that I suggested as one of the main representations of Gitanos and Roma among physicians and nurses.

“Hyperchondriac” conflates both the idea that Gitanos and Roma consult for the wrong ailments and the idea that they use the services too much. However, whereas the idea of consulting physicians and nurses for the wrong reasons was not limited to the representations but also appeared repeatedly in the encounters I observed, the representation of Gitanos as overusing services was absent in the encounters. Instead, the representation of Gitanos as not accessing healthcare services (or at least accessing them less than non-Gitanos) –which constitutes part of the double stereotype of Gitanos as visible/invisible (Sàez Sellarès and López Catalán 2009)- was frequently referred to during the encounters. The encounters I have analysed so far are tainted by this representation of underuse: in the ethnographic vignette with the gynaecologist, the first questions she posed to the patient were about the reasons why she had not had previous prenatal care, and in the clinical encounter between Lucia and Azucena both the previous bandage applied by Azucena’s neighbour and her refusal to undergo surgery signaled the infra-use of healthcare services.

This underuse of healthcare services is explained in different terms in each encounter: Azucena’s delayed search for care is explained in terms of a gendered identification while Alba’s behaviour is racialized and explained in cultural terms. But there is another difference between the encounters in terms of the biomedical underpinnings of the care offered: in Azucena’s case, what she was postponing was a treatment that

was intended to cure her condition, a straightforward causal relationship (you have a problem and this technique will solve your problem). In Alba's case, the care offered had a different quality: Alba was not suffering from an alignment; she was just pregnant and what the prenatal care offered her was not to treat something but to screen in terms of a probability of the odds of some disease happening. Prenatal care is one of the classical examples of the preventative logic, which is widespread not only in the biomedical ethos but also outside of the "clinic", where discourses about healthy lifestyles, food or environments abound. Preventative logic is one of the attributes that the "sanitary citizen" (Briggs and Mantini-Briggs 2003), or "biological citizen" (Rose and Novas 2008) must embrace to monitor herself, incorporating "healthy habits", and maintain the fantasy of being able to reduce the uncertainty of suffering a disease. Some researchers have stated that this so-called bio-medicalization means that

'health itself and the proper management of chronic illnesses are becoming individual moral responsibilities to be fulfilled through improved access to knowledge, self-surveillance, prevention, risk assessment, the treatment of risk, and the consumption of appropriate self-help/biomedical goods and service' (Clarke et al. 2003).

The next encounter I present delves into the logics of preventative measures and how preventive timing is articulated in encounters with Roma and Gitano patients.

### **Higher risk or ethnic pride**

Juan (a nurse) called me from the treatment room: he was attending a Gitano and invited me to enter. When I walked into the room, I saw Marcos, a man in his late sixties, sitting there, bare-chested with his hair in a mess. Juan was next to him looking at something on Marcos' head. He had come today to remove the staples from a wound on his scalp. In part to justify my presence and to 'break the ice' I asked him how he got injured; he replied that he had been fixing something in his car. He added -signalling the scar that crossed his chest- that he wanted to make 'one to match this one'. I asked him what had happened to cause the chest scar and he replied that he had his chest opened in halves because of a "plumbing problem" six years ago. He told us the name of the surgeon (whom none of us knew but Marcos mentioned as if we should know) and Juan replied that we did not know him. Marcos continued, telling us the details of his surgery: he had three

obstructed “veins” and he had had them replaced. He added that everything had gone fine.

Juan was now sitting at the desk looking at Marcos’ clinical records on the computer. Despite being in the treatment room, Juan took advantage of the opportunity to advise Marcos to come and visit him more frequently, because the last time he had been in the consulting room was six months ago. Juan, in a joking manner, told Marcos that he was not asking for a monthly visit or one every two months, but one visit every quarter. ‘Is that asking too much?’ Marcos said nothing but shook his head to say no while buttoning his shirt. Juan offered to schedule an appointment with him in two months, but Marcos told him that he had better not do so, because he was not sure if he was coming. Juan said nothing, but this time he was the one shaking his head saying no. After a short silence in which Juan continued looking at the computer screen and Marcos stood up and moved in front of the desk, Juan asked another question, this time about Marcos’ blood pressure. Marcos replied that his blood pressure was fine and Juan asked him how he knew that. ‘I just know,’ Marcos replied. Juan told Marcos to go back to the chair and sit there so that he could measure his blood pressure. Marcos obeyed, sat on the chair and diligently extended his arm so that Juan could place the blood pressure measurement sleeve. The reading was fine and Marcos did not have high blood pressure, as he already knew. Not adding any other comment about it, Marcos told Juan that he needed to come in a month ‘to get that vaccine, you know, for tetanus’. Juan gave him an appointment and informed Marcos that he might not be there at that time, but that someone would replace him.

Marcos, when leaving the room, said, “We Gitanos are a special race”, to which Juan and I asked, ‘in which sense are Gitanos special?’ Marcos, already outside of the treatment room, said: ‘We are just special’.

After Marcos had gone, Juan and I started chatting about the consultation. Juan was surprised about the pride that some Gitanos show when telling others that they are Gitanos (as Marcos had ten minutes before). He added a comment about the difference between not being Gitano and not repeating it all the time. We continued talking a little bit more about Marcos, and about how a lot of Gitanos have cardiovascular diseases in their sixties or before. Juan explained that it is a consequence of their lifestyle, even as a

professional disease, as it is connected with flamenco music and nightlife. Juan thinks that it is because of alcohol and tobacco that they have more cardiovascular disease.’

(Extract from my fieldwork diary)

### **Prevention time**

In this encounter, similarly to the previous encounters analysed, it seems there is a discrepancy between the reasons why patients seek attention and what are considered to be the important health issues for physicians and nurses. As in the previous vignette, the nurse took advantage of what he considered to be a trivial health problem (dressing an injury) to bring to the forefront other health issues that, in his opinion, deserved more attention (secondary prevention after a heart attack). I show this vignette because it is representative of two phenomena that I saw repeatedly during my fieldwork: first, the vignette illustrates some of the different stances regarding preventative measures and the complex rapport between physicians and nurses and Gitanos when it comes to following preventative programs, which ultimately frame Gitanos and Roma as ill-timed patients. Secondly, it shows the versatility of nurses and physicians to mould their practice to go beyond the immediate to encompass a broader health approach, which in turn reflects upon the perseverance of these nurses and physicians to insist on what they come to frame as “lost cause patients”.

The preventative paradigm in medicine establishes a specific relation between time, the body and the responsibilities of individuals to maintain good health. Preventative reasoning is a situated form of moral reasoning in clinical arenas, which entails an understanding of the role of patients as ‘active partners in the drive for health, securing their own well-being’ (Rose 2001) and the role of physicians and nurses as mere facilitators for individuals to achieve the objective of maintaining their own health. The preventative ethic prompts us to act in a way that entails an understanding of time in which the contemporary is moulded by the desire for a certain future, or as Rayna Rapp puts it, ‘managing the vital present in the face of an uncertain future’ (1999, 62).

Hence, Juan, the nurse in this encounter, enacted the role of facilitator: he checked Marcos’ clinical records and encouraged him to follow what in biomedical terms was

a good follow-up plan to help him monitor his cardiovascular risk: the secondary prevention protocol. The secondary prevention protocol is the set of techniques that aim to reduce the risk of having a cardiovascular event (mostly a heart attack) after having suffered a previous one.<sup>82</sup> These prevention techniques consist of a chronic treatment with some drugs, maintaining blood pressure and blood lipids in an adequate range and adopting an active lifestyle while avoiding some kinds of sports. Although Juan offered a follow-up, the burden of the management of the risk was placed on the patient. The nurse thus became a facilitator for Marcos so that he could learn how to identify risky behaviours, what to eat and what to avoid, tasks that ultimately are the sole responsibility of the patient. Juan facilitated the possibility for Marcos to regularly check that the odds of having a new heart attack were low. These secondary prevention techniques encompass an understanding of health and disease in probabilistic terms; this protocol promotes a routine for regular monitoring and vigilance with regard to the body in order to decrease the risk of a second cardiovascular event.

In a biomedical context, the word risk designates an array of ways of thinking that calculate the odds of probable futures in the present. Biomedical risk has a specific genealogy; on the one hand, there was a rise of statistics during the 19th century as a means for states to intervene and manage their citizens as a social body (Porter 1988) and they were subsequently incorporated into biomedical research (Hacking 1990). On the other hand there has been a standardization of medical practice and a rise of evidence-based medicine (Timmermans and Berg 2003) aimed at reducing the differences in healthcare provision for accountability and rationalization purposes. Risk works as ‘calculative rationality’ (Dean 1998) that determines the occurrence of a condition in a given population based on a large-scale data-set. Thus, as Veronica Lupton conveniently signals, ‘When patients visit their doctors, for example, their symptoms are not only treated as specific to them as individuals, but as manifestations of the patient’s location in a wider socio-demographic context’ (Lupton 1999, 131).

---

<sup>82</sup> The primary prevention protocol is the set of techniques that aim to reduce the odds of having a first cardiovascular event.

This rationale is evident in the previous vignette: Juan did not treat Marcos as just one individual who had injured himself while repairing the car, but rather he positioned Marcos in a social and demographic location that predisposed him to suffer from certain diseases. As I recalled in my field notes, Juan linked the fact of Marcos identifying as Gitano with a higher risk of cardiovascular disease, a link that was itself confirmed by Marcos' previous heart attack. If teenage pregnancy is linked to Gitanos, physicians and nurses similarly connect higher cardiovascular risk with Gitanos. For example, one general practitioner had no doubt about the higher risk for Gitanos:

“They have a higher cardiovascular risk; the reason? I do not know if it is due to their living conditions, if it is the race [...] but when a Gitano comes [...] well I think oooh! Gitano, Gitano, no worries... and higher cardiovascular risk and diabetes”<sup>83</sup>.

The causes of this perceived higher risk are explained with the available explanatory models within biomedicine to understand causality: it is either due to their lifestyle, as Juan suggested when relating the higher risk to smoking and drinking in the *tablaos Flamencos*, or to their living conditions, as this physician suggested:

“They have a worse follow up, for sure! But apart from that they have more risk and at a younger age [to suffer cardiovascular diseases]. Of course, they are men and women that, as I say, start living earlier”.<sup>84</sup>

It is interesting to note that this physician connected higher cardiovascular risk with teenage pregnancy, as she thinks that maybe the higher risk is due to the fact that Gitanos ‘start living earlier’, an expression that implies that they perform what are considered adult tasks (reproduction included) earlier than non-Roma. The idea of Gitanos not taking care of their bodies properly and not following medical advice was mentioned in most of the interviews and it was present in quite a lot of the practices, too. Not engaging with risk-avoiding behaviour is considered ‘a failure of the self to

---

<sup>83</sup> es que tienen el riesgo cardiovascular más alto ¿motivo?, no sé si es las condiciones de vida, si es la raza... pero yo cuando viene un gitano de eeeemmm, digo uy!! Gitano gitano me da lo mismo y RCV y diabetes más alto

<sup>84</sup> que se controlan peor si, pero aparte tienen mucho más riesgo y mucho más jóvenes. Claro son hombres y mujeres que también empiezan a vivir antes como yo digo



take care of itself, a form of irrationality or simply a lack of skilfulness' (Greco 1993, 361). Thus, the representation of Roma and Gitanos as bearers of an intrinsic unruliness is translated at primary healthcare clinics in terms of not embracing the preventative care of the self, of being "irrational" because of their refusal to engage with risk-avoiding behaviours in the terms that biomedicine proposes. This is how the idea of Gitanos and Roma as ill-timed individuals appears, as they are perceived as not taking care of their bodies at the right time for the biomedical ethics of prevention.

In that sense, it is interesting to note how Juan took it for granted that Marcos would not agree to come to the secondary prevention protocol visits and tried to adapt the protocol to a "lighter" version (*a visit every three months, is that asking too much?*). Still, his attempt was in vain and Marcos resisted the imperative of monitoring. So Juan offered to measure Marcos' blood pressure despite the consultation not aiming to check Juan's cardiovascular risk factors. Juan was enacting a form of care that went beyond the standardized practice to adapt to the patient's values without abandoning the biomedical understanding of what the best care for the patient was. Juan's practice can be framed as what Annemarie Mol (2008) refers to as 'doctoring'<sup>85</sup>, as he was experimenting with the knowledge and technologies he had to attune them to Marcos' needs. Mol suggests that doctoring 'depends on being knowledgeable, accurate and skilful. But added to that, it also involves being attentive, inventive, persistent and forgiving' (2008, 64).

Despite the fact that Juan presumed that Marcos would not want to monitor his cardiovascular risk –a presumption in relation to the representation of Gitanos as a lost cause- he still offered what could be a more suitable schedule for his patient, and when it was refused again, he offered to check it at that very moment. Juan was attentive to Marcos' preferences and invented new ways to adapt to them, persistently offering his knowledge to help Marcos take care of his body. Nevertheless, Juan was convinced of the low odds that his persistence would lead to Marcos changing his mind and engaging in preventative care. However, Juan's –and Lucia's in the

---

<sup>85</sup> Mol acknowledges the pejorative connotations that the word doctoring has, but she aims to rehabilitate the word to refer to the logic of care in its own terms.

previous vignette- persistence is part of their ordinary practice, widening their understanding of their professional role so that they are not just a facilitator who provides options for the patient to choose from at a specific moment.

Finally, the vignette “confrontation” between Juan’s need for prevention and Marcos’ trust in his body (a Gitano body) ended up with Marcos asking for an appointment to get a vaccine shot and thus showing Juan that he would come back to the healthcare centre and take care of himself. Vaccination is part of the preventative measures offered at the healthcare centre, and it also entails an understanding of health and disease in a preventative biomedical logic. Notwithstanding this preventative ethic, Marcos was willing to vaccinate. Thus, the relationship of Gitanos and Roma with preventative programs is not as straightforward as healthcare professionals frequently picture it.

## **Concluding Remarks**

In this chapter I have analysed through three different ethnographic vignettes the repertoires of practices in relation to Gitanos enacted in clinical encounters. The idea that Gitanos are ill-timed patients takes a different meaning at the consulting room as it makes reference both to Gitanos’ reproductive patterns (their social body) and their relationship with their own body. Either due to their “old-fashioned” gender roles (like Azucena) or because they do not follow preventative programs in the suggested manner (like Marcos), Gitanos are represented as not embracing modernity and therefore different from Payos and, to some extent, backwards. Backwardness and unruliness get entangled in these representations of Gitanos as ill-timed, in a clinical arena where time is both a precious resource, a guiding principle for practice and condition to build a specific type of patient-physician relationship. In the next chapter, we move from the primary healthcare centre and its organizational logics to investigate the practices at the healthcare van.

# **Chapter Four: The Healthcare Van**

## **Introduction**

In this chapter I analyse the clinical practices of a special primary healthcare service that operates as a mobile clinic for the people living in an informal settlement. Previously I analysed the representations that link Gitanos with substandard housing and irregular settlements and how this link prompts a construction of Gitanos as illegitimate citizens, inasmuch as they live in these irregular settlements, places for the “socially excluded” and therefore are without public services and basic rights. These places are what in the admission desk chapter I call islands of non-citizenship. Before going into detail about ordinary clinical practices in the healthcare van, I will offer a brief analysis of the factors that prompted the creation of such a primary healthcare service. This analysis is necessary to better understand the institutional logics that underpinned the creation of the healthcare van services, as well as the problematization of a group of people as ‘individuals to be corrected’. After the introductory background section, I will analyse clinical practices in the van and the meanings that cultural difference acquires in this clinical space.

## **1. Configurations and Representations**

### **1.1 Participation Without Participation**

The healthcare van where I conducted my fieldwork is the only service of its kind in Madrid. The van was conceived of in 2006 and started providing healthcare in 2007, in two of the remaining settlements on the southern outskirts of Madrid. But why was such a healthcare service set up to attend to the settlement dwellers while the mayor’s office was implementing a special programme to “eradicate” Madrid’s informal

settlements? In what follows, I aim to disentangle the multiple factors that made the creation of the healthcare van possible. First, I will examine the institutional configurations -specifically the interdisciplinary council where the van was designed- and the way the settlements are problematized. Secondly, I will explore the influence of a tuberculosis outbreak to build on the representation of the settlement as a healthcare emergency. Finally, I question the tensions emerging from the creation of the healthcare van and how they were solved.

The development of primary healthcare in Madrid during the 1990s took into account the provision of different spaces for citizens' participation in institutional decisions. Those spaces, known as *Consejos de Salud* (local health councils), involved citizens, healthcare workers, associations, social services, and any local residents who were interested in health issues. Distributed unevenly, not every primary healthcare centre successfully developed its *Consejo de salud*, but in the southern working-class neighbourhoods –which have a longstanding tradition of participation and a well-developed social fabric<sup>86</sup> - they were visible and more active. Partly because of the HIV epidemic in the 1990s and its association with drug use and the existence of different irregular settlements in the area, the *Consejo de salud* at the primary healthcare centre on the periphery decided to create a different council to exclusively address the complex and urgent health issues of the irregular settlements that did not leave time to discuss the “ordinary” health issues of the neighbourhood. The informal settlements were no longer a neighbourhood problem but a problem for the neighbourhood that needed to be addressed by different institutions with professional strategies. The new council was called “*Comisión de población excluida*” (CPE), which stands for Socially-Excluded Population Council; its first meeting took place in 1998 and it has met monthly since. Although the main purpose of the *Consejos de salud* was to facilitate citizens' participation, the CPE was conceived of as a professional and inter-institutional forum, and citizen participation was not envisioned. Dealing with the so-called socially-excluded population's health issues was framed as a professional

---

<sup>86</sup> In this respect, it is interesting to note the importance of the neighbourhood associations during the final years and in the aftermath of Franco's dictatorship. These associations were in charge of dealing with every aspect of everyday life, creating a prolific social fabric in a context of political repression (Castells 1983).

matter, directly excluding the population from participating in the meetings. Thus, the name of the council became a self-fulfilling prophecy and the health issues of the settlements' inhabitants were differentiated (and excluded) from the health issues of the rest of the neighbourhood.

Following the *Consejos de Salud* tradition, the CPE is hosted by the healthcare institution but workers from other institutions, NGOs or charities attend the meetings regularly. Analysing the health status of the people living in the settlements, promoting coordination between the different actors in order to optimize resources and raising awareness of the difficult living conditions in the settlements are the main objectives of this council (Salud Madrid 2005). In order to raise awareness of the difficult living conditions, the CPE issued a report in 2005 entitled “*Situación de los Asentamientos Marginales del área Sanitaria 1*” (Living Conditions in the Marginal Settlements of Healthcare Area 1) in which the council suggested the possibility of creating a healthcare van to work in the settlements to provide emergency care and ‘get that population (the settlement dwellers) back into regular healthcare circuits’ (2005). The report merits further analysis as it displays how the CPE problematized the informal settlements and the kind of interventions proposed to solve those healthcare problems.

## **1.2 The CPE Report: Recognition Through Normalization And Eradication**

The CPE report draws on the professional experience of the council members and secondary sources to give a description of the settlement, analyse health hazards and propose measures to reduce those hazards. Divided into seven sections the, main body of the report comprises the description of the settlements in four different categories: general location and surroundings, population characteristics (demographic, ethnic, socioeconomic position...), housing conditions, and finally, the so-called socio-sanitary characteristics. Ariadna Ayala Rubio, an anthropologist and former member of the CPE, analysed the discourse of the report and she highlights how the council members tended to take for granted the ‘good intentions’ of their interventions while they built a positive image of themselves that contrasts with the negative construction of the population in which they intervened (2012, 170). As Ayala further argues, while the interventions are not questioned, the population is

described in terms of multiple deficiencies and criminal activities, reinforcing their social stigma without analysing the historical, economic, social and political context in which social exclusion is produced (Ayala Rubio 2012, 180). In a similar fashion, Loïc Wacquant (1997), in his analysis of the literature about the American Ghetto, signals that the ‘trope of disorganization’ prevails in most social research on the Ghetto. For Ayala, by not taking into account the point of view of the socially-excluded population, or the critical analysis of the institutions that intervene in them, the report becomes ‘a compendium of the author’s opinions... with the only purpose of increasing the number of professionals intervening with socially-excluded populations’ (2012, 171).

Beyond the contrast between the positive image of the professionals and the negative description of the settlement dwellers described by Ayala Rubio (2012), there are two other pairs of opposed notions that permeate the CPE report (Salud Madrid 2005): one is the opposition between normalized/non-normalized and the other is the notion of eradication/perpetuation. The latter pair is frequently used to refer to the tension regarding proposing institutional interventions in settlements, which those same institutions aim to make disappear. To solve this apparent contradiction, the interventions proposed should help in achieving the ultimate goal, which is to eradicate the settlements. Therefore, institutional interventions are not intended to provide public services in the settlements – because those services could perpetuate the existence of the settlement- but to help in the mobilization of the settlement dwellers to places with public services. In the report there is a continuous justification about how the proposed measures (and the report itself) fight against the perpetuation of the settlement, as the following quote shows:

‘It is important to note that this report and the upgrading actions proposed ... are *not expected to perpetuate this situation but just the opposite, to contribute to making this population closer to normal social situations*’<sup>87</sup> (Salud Madrid 2005, 1, emphasis in the original, my translation).

---

<sup>87</sup> ‘Es importante destacar, que el trabajo aquí presentado y las acciones de mejora propuestas... *no pretenden perpetuar esta situación, sino por el contrario contribuir al acercamiento de esta población a situaciones de normalidad social*’

In this quote, the emphasis is placed on not perpetuating a situation that, for the report's authors, maintains people far from social normality; the settlement is, therefore, a place of abnormal social situations. The report builds on this normal/non-normal opposition by presenting the settlement as a non-normalized space whose dwellers have to be re-socialized (or normalized) to be included in normal spaces. That is the purpose of the institutional measures to help in this process of normalization that will ultimately contribute to making the settlement disappear. The idiom of normality is used throughout the report to indicate that the institution is the space of normality and the settlement (and its inhabitants) is outside of this space, and therefore interventions aim to bring the population closer to the space of normalcy. In this quote the use of the Euclidean space metaphor to refer to citizenship (or lack of) is clear. Multiple references to 'normalized healthcare' and the 'normalized healthcare network' abound in the report, as these quotes show: 'the settlements described are areas in which there are no normalized healthcare services'<sup>88</sup> (Salud Madrid 2005, 18) or 'difficulties in vaccinating this population in a normalized way, which involves the risk of a higher incidence of certain diseases avoidable through vaccination'<sup>89</sup> (Salud Madrid 2005, 31).

The CPE report functions, in Foucault's terms, as a discourse of truth (Foucault 2003a) insofar as it is a discourse with a scientific status expressed by qualified people within a scientific institution. CPE members are granted expertise in social exclusion within the different institutions for which they work, and their opinions are taken as scientific inasmuch as they are based on their professional experience. Foucault, in his lectures at the College de France in 1975, addresses the question of the "abnormal" drawing on the analysis of expert psychiatric discourses in penal cases since the nineteenth-century. Foucault aimed to study

'the emergence of the power of normalization, the way in which it has been formed, the way in which it has established itself without even restricting on a

---

<sup>88</sup> 'Los asentamientos descritos son zonas aisladas en las que no se encuentran ubicados dispositivos públicos de atención sanitaria normalizada'

<sup>89</sup> 'dificultades para la vacunación normalizada de la población, lo que conlleva un riesgo de mayor incidencia de ciertas enfermedades'

single institution but by establishing interactions between different institutions’ (2003a, 26).

In these lectures Foucault highlights the shift in expert psychiatric discourse from discerning whether the suspect was suffering from dementia at the time of his action (and therefore not being accountable for the offence) to a discourse that establishes whether there were mental characteristics in the suspect that could be connected to the offence (2003a, 25). Expert psychiatric opinion becomes disconnected from the scientific and rational normative structure and adopts new rules of formation within the legal discourse (2003a, 24), becoming part of the techniques of normalization.

A similar transformation into a specific technique of normalization<sup>90</sup> can be observed in the medical discourse used in the committee report: the medical discourse moves from determining whether material conditions are causing illness to describing the extent to which the marginal population’s behaviour contributes to their own exclusion. To illustrate this kind of discourse I translate a quote from the report:

‘The socio-cultural characteristics of the different groups of the population that live in these areas determine their use of the social and health care services. Thus, illiteracy, non-proficiency in the language, *their own idiosyncrasy and the particular understanding of health for some groups*, shape their inadequate understanding of administrative processes and the health care tempo. All of this determines that with great frequency exceptionality is the only care path’<sup>91</sup> (Salud Madrid 2005, 19 emphasis mine, my translation).

---

<sup>90</sup> The whole healthcare institution can be analyzed in Foucault’s terms as a disciplinary institution based on different techniques of normalization, known, in Foucault’s terms, as biopolitics. However, even I acknowledge and agree with the power of normalization of biomedicine itself. Here I look at how biomedical discourse intertwines with social discourses about marginalization to problematize a marginal population, under a set of rules that is different from biomedical discourse but presented as such. In a way, it is as if the marginal population is impermeable to the normalizing discourse of biomedicine and a different technique of normalization is needed to reach them. I use problematization in Foucault’s sense: “Problematization does not mean representation of a preexisting object, nor the creation by discourse of an object that does not exist. It is the totality of discursive or non-discursive practices that introduces something into the play of true and false and constitutes it as an object for thought.” (Foucault 1994: 669–670)

<sup>91</sup> The original quote in Spanish is: ‘Las características socioculturales de los distintos grupos de población que viven en estas zonas van a determinar la forma de utilización de los servicios socio-sanitarios. Así, el analfabetismo, el desconocimiento del idioma, la propia idiosincrasia y el particular concepto de salud de algunos grupos, influyen en la inadecuada comprensión de los procesos



In this paragraph we can appreciate the construction of a marginal population as not only lacking the personal resources necessary to access social and health care, but also as bearing certain attributes (their own idiosyncrasy and particular understanding of health) that distance them from normalcy and determine an inadequate and ‘exceptional’ use of services. Those features, which in the eyes of the experts are barriers to citizenship, become the justification for the intervention: institutional intervention is necessary to modify the inappropriate use of services and promote a normalized use. Throughout the report, the marginal population is compared with what they refer to as the ‘normalized population’. This comparison implicitly marks the settlements’ inhabitants as a non-normal population and problematizes them as people in need of different normalization techniques. In sum, the settlement dwellers are problematized as ‘individuals to be corrected’ (Foucault 2003a) through the expert knowledge constructed by the interdisciplinary members of the CPE.

The healthcare van’s design was embedded in the debates held at the CPE meetings and reflected in the report. These debates revolved mainly around how to address the need to make the settlement disappear while improving the health conditions of its dwellers in the meantime, or how to balance the risk of perpetuating a situation of social exclusion with measures aimed at resolving that situation. Furthermore, the debate about the pertinence of creating a healthcare van to attend to the settlement dwellers on the ‘island of non-citizenship’ underscored the different positions of the CPE participants regarding ideas of equity and social justice. Those participants opposing the creation of the healthcare van argued that it would be a positive discrimination measure that would help to perpetuate the existence of the settlement and to discourage the re-socialization (or normalization) of the settlement dwellers to use the “normalized” healthcare services. On the other hand, those participants supporting the healthcare van’s creation contended that it was a matter of social justice for the services to approach those who were more vulnerable to disease and had more difficulties in accessing “normalized” healthcare facilities. Finally, as a

---

administrativos y ritmos del sistema sanitario, lo que determina que con gran frecuencia la única vía de atención sea la de la excepcionalidad’.

consensus agreement, and in concordance with the whole set of measures proposed in the report, the CPE envisioned a healthcare van that did not attend to the settlement dwellers, but rather in case of emergency; instead of providing care, the van was conceived of as a mediator in charge of informing people about how to access “normalized” healthcare services.

My argument is that the idiom of ‘normality’ is frequently used to refer to the van because everything related to the settlement is considered ‘abnormal’: in the CPE report the settlement dwellers are described as having multiple deficiencies (not suffering from these deficiencies), which makes them exhibit non-normalised behaviours and lifestyles (corroborated by their non-normal use of different services). The report served as the empirical background to design the healthcare van and its main objectives. Consequently, the main aim of the van was to work on the re-socialization of the so-called “socially excluded” into regular healthcare instead of actually providing them with healthcare. To avoid the danger of perpetuating the problem they aimed to solve (the healthcare exclusion of the settlement dwellers), a unit such as the van should just provide care in case of emergency or for patients who are not entitled to healthcare and need some kind of medical care. Similarly, those who are considered not responsible for their exclusion (children, and to some extent pregnant women as carriers of a child-to-be) can be attended to at the settlement. Despite the CPE report envisaging the healthcare van, the report did not in itself foster the van’s launch. There was a fundamental event (in Povinelli’s sense) that ultimately triggered the van’s creation: a tuberculosis outbreak in an area of the settlement, which I analyse in the next section.

### **1.3 Tuberculosis And Its Threats**

During 2006, three cases of tuberculosis were diagnosed at one of the paediatric hospitals of Madrid. These cases were peculiar: not only did the children afflicted present with an unusual disease, but also they were also three siblings from a Romanian Roma family who lived in an informal settlement. Although still relatively frequent in some areas in Madrid, tuberculosis is not a common disease: it is a matter of public health and every diagnosed case is notified to the local Public Health professionals who undertake examinations in order to identify the index case and prevent the further spread of the disease. Occasionally, public health authorities can

restrict the freedom of those patients whom they suspect of irregular compliance with treatment. Thus, tuberculosis is one of those diseases where an individual's rights are suspended for protection of the collective.

The children diagnosed were living in a makeshift shack settlement located just next to the “migrant nomads’ integration project camp” (APOI project) and adjacent to the informal settlement. As I previously explained in chapter one, the project camp was the institutional response to address the ‘social emergency’ posed by the first Roma migrant settlements: the makeshift shack settlement was formed by those families who were no longer part of the APOI project but had not managed to “integrate” and wanted to remain close to their extended family members who were still at the APOI project camp. When the first Roma child was diagnosed with tuberculosis, public health workers contacted social services to locate the family and initiate a search for the tuberculosis index case. Social workers were overwhelmed by the need to handle a health issue that exceeded their competences, so they asked for help at the local primary healthcare centre. In addition, social workers raised the problem at one of the CPE meetings and managed to engage one physician and one nurse from the primary healthcare centre to investigate whether there were more susceptible people in the settlement. Together with the public health professionals and the social workers, the primary healthcare workers managed to identify and treat the index case and gave early treatment to those people who were susceptible to developing tuberculosis.

Despite the adequate coordination between different institutions (facilitated by the CPE meetings) and the successful intervention to halt the tuberculosis outbreak, a sense of medical emergency concerning Roma emerged at the CPE. In the eyes of the social workers the three child tuberculosis cases could have been avoided if Roma had better access to healthcare. These social workers had to deal with a disease that they perceived as a threat to themselves and about which they knew little. Tuberculosis was not only a health issue for the settlement dwellers; it transformed them into a health threat that had to be controlled. Tuberculosis has been historically conceived of as a ‘social disease’ connected with poverty (Dubos and Dubos 1952) and recently with immigrants (Kehr 2012). Tuberculosis is a “social disease” (Barnes 1995), archetypical of inequalities. Janina Kehr, in her research about the governance of tuberculosis in contemporary Germany and France, describes how ‘in Western

Europe in the 2000s, TB is only thinkable as a disease of the Other, linked to an elsewhere, either temporal or geographic. And it is a social disease without a future, linked to poverty'(2016, 4). The tuberculosis cases in the settlement confirmed the representation of Roma as people from an elsewhere, but on this occasion, that elsewhere became a threat to the here and now that needed to be addressed. Therefore, the conceptualization of Roma as a 'health emergency' instead of the initial 'social emergency' gained weight after the tuberculosis cases.

What it is interesting is to analyse how after the tuberculosis cases there was a shift in the nature of the intervention proposals aimed at Roma living in the settlement. In the 1990s, when UNICEF and the ombudsman denounced the unsanitary conditions of the Malmea settlement, the interventions they proposed aimed at upgrading the living conditions at the settlement or, put in a different way, treating the social causes of health problems. After the tuberculosis cases, however, the CPE's proposal was to tackle the healthcare problems directly and the recommended intervention was to launch the healthcare van to diagnose and control new tuberculosis cases early on. The problem was not that the unsanitary living conditions of Roma were compromising their health, but that their health problems could eventually become a public health issue. My argument is that proposing an upgrading of the new settlement was not considered to be a legitimate proposal because a 'social project' had already been implemented (the APOI project). Therefore, the Roma' settlement in the vicinity of the APOI project was perceived as a consequence of the Roma's unwillingness to comply with the requisites of the integration project and accordingly, it was conceptualized as the Roma' choice to live in irregular/illegal conditions.

Regularizing the settlement was beyond the realm of institutional interventions: the only possible way to tackle health issues while bypassing the seemingly un-addressable unsanitary living conditions was to support the creation of the healthcare van. Thus, the 'social emergency' became a 'health emergency'. The CPE embraced this discourse of 'health emergency' and their way of problematizing the settlement inhabitants played a crucial role in the van's design. In the context of the CPE, tuberculosis was a "social disease" that transformed a social emergency into a health emergency, erasing all of the social inequalities that, at first, make people more vulnerable to suffering from tuberculosis. Social inequalities are naturalized as something intrinsic to Roma: the cause of these inequalities is the Roma's inability to

integrate and comply with the “social normalization” offered at social projects such as APOI. As exposed in chapter one, the social deviance of Roma (and Gitanos) is measured against the norm of compliance and institutional interventions aim to correct their unruliness, with little success. Therefore, the argument that follows is that Roma live in unhealthy conditions because of their innate unruliness, but if they become a health threat, special measures can be taken to control them. A healthcare van was the last desperate measure that, despite aiming to re-socialize Roma to make them become citizens with full rights, was designed to restrict health threats.

### **1.4 Designing The Healthcare Van**

With the specific purpose of contributing to re-socialising the settlement’s inhabitants while containing public health threats, the healthcare van’s objectives were established mainly as a normalization technique combined with medical care within a humanitarian framework. The main objectives were described as: bridging the gap between the socially-excluded population and the healthcare system, initiating the normalization process and observing the health needs of the population who lives in the settlement.<sup>92</sup> The document continues with a detailed description of the medical services that were expected to be most frequent in the settlement: the nature of the healthcare problems listed and the order in which they are presented casts light on how settlement dwellers are represented and the main concerns they pose to the healthcare institution:

- Children and adult vaccination
- Prevention, diagnosis and treatment of transmissible diseases
- Directly-observed treatment (DOT) dispensation
- Prevention, diagnosis and treatment of drug use
- Psychopathological assessment
- Family planning, cervical cancer screening and pregnancy follow-up
- Minor surgery
- Acute pathology
- Blood and urine tests

---

<sup>92</sup> The internal document provided to the job candidates and used afterwards as the main guide to establish and negotiate the van’s services.

- Detection and referral of social problems
- Field-observation of the health needs at the settlement
- Teaching and researching aptitudes
- Ability and disposition to coordinate with social services, mental health services, public health, drug abuse treatment services, Samur,<sup>93</sup> local police and NGOs.

This list shows the dual role of the van as a care and control service: ‘The tensions between compassion and repression, the problems posed by the mobilization of empathy rather than the recognition of rights, the prejudices towards the dominated and their consequences regarding the way to treat them’ (Fassin 2011c, X). Care is provided on the basis of humanitarianism to children and pregnant women and to those who suffer an acute health problem, but it was not contemplated that the van would provide healthcare to those with chronic diseases. It is not about rights but about mobilising empathy, as Fassin described. In this logic, people suffering from a chronic disease must use the ‘normalised’ healthcare network and they will only be attended to in the van in case of emergency. The prejudice towards the people in the settlement (adults are to some extent perceived as responsible for their exclusion) causes a lack of empathy regarding male adults and justifies repressive measures. In the logic of normalization, caring for patients with chronic diseases represents an example of positive discrimination and a contribution to the non-desirable perpetuation of social exclusion. The emphasis on transmissible diseases made for the inclusion of DOT –which is not included in primary healthcare- on the list of services, highlighting the control side of the healthcare van. Furthermore, the addition of DOT to the van’s services concurs with the event that prompted the healthcare van’s creation: the tuberculosis cases in the settlement. Directly-observed treatments are uniquely used for tuberculosis treatment because of the public health risk of transmission or multi-resistance if treatment is not followed. Controlling the threat that untreated or badly treated tuberculosis represents is part of the van’s mission and that is why they have to monitor and carefully observe the settlement inhabitants.

---

<sup>93</sup> Samur is a specialized medical emergency system in Madrid. The name stands for Servicio de Asistencia Municipal de Urgencia y Rescate, which means Municipal Emergency and Rescue Service, and has a social counterpart called Samur Social, which is in charge of social emergencies.

Besides, the inclusion of DOT in the van's services takes for granted the idea that the settlement inhabitants would not correctly take the tuberculosis medication; they are presumed to be non-compliant patients and therefore directly-observed treatment is necessary. Paradoxically, DOT is not framed as a positive discrimination measure even though it entails free treatment and personalised care at home; DOT pertains to securitarian discourses conflated with the logic of humanitarianism (Alunni 2015). But tuberculosis is not the only disease to monitor, there are other threats that need surveillance: drug users, mentally ill patients and population growth. Settlement inhabitants are not only at risk themselves but they represent a risk to others, and therefore exceptional control measures are justified.

Danger, public health risk and multiple deficiencies are stitched together in the experts' construction of the marginal population, as reflected when they sketch the different institutions that the van has to coordinate with: social services, NGOs, public health and, of course, the police. Paradoxically, some of the people who contributed to making the CPE report and drafting the van's tasks had been working in the settlement for some years. Despite providing quite a detailed account of the settlement population (demographic data, statements about income, etc.), the report acknowledges that there is little awareness about the healthcare problems of the settlement's inhabitants and thus the healthcare van should contribute to generating that knowledge. Hence it seems that the objectives of the healthcare van were proposed on the basis of a stereotypical image of the people who live in the settlement, building a profile of the inhabitants that could justify the unquestionable need for intervention. Here again, the double stereotype of visibility/invisibility described by Sàez Sellarès and López Catalán (2009) shapes the representations of Roma and Gitanos and the interventions aimed at improving their health (such as the healthcare van).

## **2. Interstitial Practices**

The healthcare van is not only about monitoring, but also entails the recognition of a population that is systematically excluded. Fassin, when describing humanitarian government, reflects on this duality of recognition and control:

‘A remarkable paradox deserves our attention here. On the one hand, moral sentiments are focused mainly on the poorest, most unfortunate, most vulnerable individuals: the politics of compassion is a politics of inequality. On the other hand, the condition of possibility of moral sentiments is generally the recognition of others as fellows: the politics of compassion is a politics of solidarity. This tension between inequality and solidarity, between a relation of domination and a relation of assistance, is constitutive of all humanitarian government’ (Fassin 2011c, 4).

The van’s project came to light under the logic of humanitarianism: its main objectives were defined as a mixture of recognition (provide healthcare to the people of the settlement) and control (limiting this provision of care to just certain cases and focusing on minimalizing public health threats). Despite the healthcare van being devised to bring healthcare services to those framed as ‘hard to reach’ and thereby to circumvent the barriers to effective access to healthcare, the van’s list of tasks reproduces the administrative obstacles to effective universal healthcare. The same ‘quotas of legitimacy’ that operate at the admission desk are reflected in the van’s objectives. However, as there is no admission desk or administrative staff in the van, both the physician and the nurse are in charge of informing about the requirements to obtain a healthcare card.

So not only do the van’s workers attend to “some of” the health conditions of the settlement dwellers but are also crucial to the administrative tasks to obtain healthcare cards, as the division between administrative and healthcare staff that organises the work at the healthcare centre disappears in the van. Apart from this difference from the more traditional roles physicians and nurses inhabit at primary healthcare centres, it is also noteworthy to analyse the van’s position within the healthcare system and the challenges it poses to established professional roles. Being part of the public healthcare organization but working outside of the “institutional space” (which would be the hospital or the healthcare centre) in a social space presented as an ‘island of non-citizenship’, the van’s workers are both inside and outside of the healthcare institution. They operate outside of traditional healthcare facilities, in a position that Anne Lovell (1997) has described as ‘interstitial’. Based on her research into services that work with homeless people in New York, Lovell describes the outreach teams that provide psychiatric care to homeless people as interstitial organizations that exist in between psychiatric and social services.



‘Often relegated to the tasks of providing emergency solutions (psychiatric or not), identifying potential clients, convincing them to use mental health services, or referring them on to other services, they legitimate their actions on the basis of a highly ambiguous, never fully articulated authority’ (1997, 357).

Lovell (1997) also highlights the need of these interstitial organizations to be ‘nomadic’ in order to reach the non-places where their clients live. The healthcare van thereby could be defined as an interstitial service because of its work in between the normalized space of the healthcare centre or the hospital and the non-normalized space of the settlement. Or to put it differently, the healthcare van is positioned in the virtual space between the space of citizenship (the clinic) and the ‘island of non-citizenship’ (the settlement). In fact, the institutional description of the van’s work is “to bridge the gap between the socially excluded population and the normalized healthcare network”, a description that perfectly matches the definition of interstitial organizations. Similarly, the van’s mobility defines its work as interstitial, permitting the van’s workers to approach those patients who live in the settlement and to go over the old cattle track that the settlement used to be.

Both the van’s mobility and its location outside of traditional healthcare facilities influence the way the van’s workers understand their work, their role within the healthcare system and the multiple ways they cope with the contradictions they face in their ordinary practices. Similarly to other nurses and physicians, the van’s workers frequently refer to cultural difference, but they tend to use it to highlight other aspects than the tensions over the allocation of resources (as was the case at the admission desk) or over therapeutic decisions (as in the consulting room). In what follows I present some ethnographic examples to analyse the meaning of cultural difference in an ‘interstitial service’ such as the van. With the first vignette I aim to better understand not only how the van was created as an exceptional measure but also how it is constructed as ‘(extra)ordinary work’. With the second vignette I delve into other aspects of the work at the van such as the conflation of public and private spaces and the organization and distribution of care. In the final vignette I analyse the different ways the van’s nurse and physician make sense of their ordinary practice and inhabit the ambiguity that entails their ‘interstitial work’.

## 2.1 “(Extra)ordinary Work”

One day in the van in my field diary:

First thing in the morning, we went to the house of a Moroccan patient for blood tests and her daughter asked us about a virginity certificate; she was getting married in Morocco and needed a certificate. We explained to her about not being able to determine whether she was virgin or not by anatomical features, and then she asked me: you do not know how to do the certificate? I told her that it was not exactly that but afterwards I admitted that I did not know how to do it. She explained to us that in Morocco doctors issue such certificates just in case, after the wedding, the new husband claims that the bride was not a virgin, which would invalidate the marriage. She would find someone in Morocco, she told us, but there she would have to pay for it.

We moved to “the henhouse”<sup>94</sup> to continue the round of blood tests. This time three women were scheduled for blood tests, all of them pregnant. Rosa, the first one, went to the gynaecologist’s appointment. I asked her about it and she replied that she did not know, that I know better... something about the foetus not gaining enough weight and the gynaecologist wanting to check every fortnight to measure the foetus. If it was not growing, they would take the foetus out and make it grow outside...

Laura had a blood test scheduled, too. She was back in the settlement after a short stay in prison [...] no prenatal care while she was imprisoned.

The last patient with a blood test scheduled was Ana. She said that she was five months pregnant and that she did not feel foetal movements; we had already scheduled three appointments at the gynaecologist for her but she had not managed to go to any of them. I called to schedule a new one, but worried that something was going wrong, I told her she could come with us to the hospital (we had to take the blood samples to the laboratory before noon) and we left her at the emergency room. She refused to come. I checked in

---

<sup>94</sup> “Henhouse” is the name of the informal settlement built in the vicinity of the APOI project camp. The camp project disappeared in 2007 but the informal settlement remains there since then. All of its dwellers are Romanian Roma.

the clinical records for how far she was in her pregnancy; it is not five but three months, and therefore it was no problem not to feel foetal movements. I felt relieved but still wondered why she had been so worried lately; she came to the van in the last weeks almost every time we went to “the henhouse”. Maybe with a Doppler foetal monitor in the van we would feel less stressed in this kind of situation.

We went to the hospital and took the blood samples box to the laboratory. Back at the settlement, we went to visit Manu, who had just been discharged from the hospital after leg-artery bypass surgery. He told us that they (the vascular surgeons) had not cut off his leg because he went to the hospital just in time “because I listened to you and went to the hospital when you told me”. Another legend was born. This was Manu’s way of showing gratitude. After cleaning the wound and checking the treatment we went to the evangelical church: some people were waiting for us there. I was distracted and told a patient on the phone that we were at the mosque instead of the evangelical church.

The first patient came in and Nuria discretely asked for a plastic cup to take a pregnancy test. The result was positive, and when I told her she was pregnant she turned pale. As there were a lot of people around and no privacy to talk about the different options I told her that it would be better if I phoned her later so we could talk without other people listening. Afterwards I called her while we were on our way to Juan’s house. On the phone, Nuria told me that she needed more time to think about it, that she did not want to make a decision she would regret for the rest of her life. I thought about how important it was for her to be a mother (she already had two children) but nevertheless she was aware of the difficulties she had in raising a child in her circumstances. She told me about the IUD (intrauterine device) she had that had fallen out, so clearly this was not a planned pregnancy. I told her we would call her back in two or three days.

At Juan’s place, there was a chronic patient suffering from Multiple Sclerosis who had been prostrate in his bed for two years now. His ex-wife had been taking care of him all of these years out of pity (she said) because he did not have anyone else to take care of him. We went to cure his bedsores twice a week and it was Sisyphean work; as soon as one healed, a new one appeared in a different pressure area. He has lost his mind some years ago and this time he insulted

us as usual “mecagüen tu raza” while we cured him. We joked with his ex-wife about Juan’s politeness and gratitude.

Outside Juan’s house a group of Moroccan women waited for us: one of them was the woman I had wrongly told that we were at the mosque when we were at the evangelical church. One of them asked about an infected wound. She told us that she had fallen down but a thought came to my mind instantly and I wondered about the relationship with her husband. It seemed I was wrong; she had fallen down during an activity to promote exercise among migrant women. She was walking with other women from her Spanish class on an unpaved road in the settlement when she tripped over a stone and fell down. The other women asked for different things, prescriptions, scheduling appointments with the dentist, renewals of the healthcare card for one of them and all her children (she had just renewed her residence permit). The phone has been ringing the whole morning; today I feel we received more phone calls than other days.

This note from my field diary provides a brief outline of an ordinary workday in the van. It is not an exhaustive description of all the activities that the van’s workers performed that day, just those I managed to remember after the consultation and note in my field diary. Looking closer at the kind of services available at the healthcare van, these services do not differ substantially from those provided at the primary healthcare centre: getting blood samples, following up pregnancies, attending patients with chronic diseases in their homes, house calls after a discharge from surgery or attending to acute health problems. All these are the kind of activities that fill the professional agendas at the healthcare centres, too. Both the healthcare centre’s and the van’s workers follow the same regulations and the enforcement of the same institutional “mission, vision and values”. To some extent, the van’s workers share the same basis of knowledge as well as the moral standards as the workers at the healthcare centre use to organize daily conduct (Douglas 1987). However, at the healthcare centre the healthcare van is perceived as “extraordinary work”. The van becomes extraordinary both because it means an addition to what regularly happens at the healthcare centre and because it occasionally provides care in unexpected or surprising ways.

That the van means an addition to the regular services of the healthcare centres seems evident. Yet, bearing in mind the original purpose of the van as a mediator

between settlement dwellers and regular healthcare services, the provision of care at the van was not contemplated except in extraordinary circumstances. Thus, the van would not be an addition to the regular services but a substantially different service. This is not the case because both the van's nurse and physician dissent from the van's original objective of simply working as mediators. The van's nurse, who has been working in the van uninterrupted since its launch, states it clearly: 'We are chiefly an "assistance-focused service" (*dispositivo asistencialista*), and it is through the care we provide that we aim to bring the healthcare network closer to the disenfranchised population we work with<sup>95</sup>'. In his statement, the nurse makes clear his position: he is rejecting the institutional van's objectives that, for him, contradict the fundamental ethos of primary healthcare (being accessible and equitable in the provision of care). Instead of endorsing the CPE discourse of "normalization and eradication" and reproducing the system of "quotas of legitimacy" to access healthcare, the van's nurse legitimizes his actions in the moral standards that shape primary healthcare as the "entrance door to the healthcare system". Being part of the primary healthcare network but having differential objectives from this service (DOT for example), the van operates in the margins of two distinctive moral orders: that of primary healthcare and the moral order of CPE. Therefore, the van's workers legitimate their actions with the moral order that is more convenient to the way they perceive their professional role, discarding those precepts that are not in accordance with their view. As Anne Lovell claims, interstitial services 'legitimate their actions on the basis of a highly ambiguous, never fully articulated authority'(1997, 357). In this case, the van's nurse defends the right to universal access and bases the van's work on that right instead of the mobilization of empathy. Yet he does not completely discard the "normalizing" potential of his work (and therefore the ultimate goal of the CPE members, which is to eradicate the settlement) as he acknowledges that providing care at the settlement is the first step to bringing disenfranchised populations into the healthcare system. Both the premises of primary healthcare and the van's objectives are subtly reconciled in the nurse's statement, displacing the van's work from a humanitarian framework to a discourse on rights.

---

<sup>95</sup> 'Somos ante todo un dispositivo asistencial, damos asistencia y a partir de ella es como trabajamos aproximar a los excluidos a las instituciones' "asistencialismo" is a frequently used idiom in this context, which has some negative connotations I will analyse later

It is interesting to note that the emphasis the nurse made on signalling that the van is an “assistance-focused service” (*asistencialismo*<sup>96</sup>) is highly controversial in the context of the CPE. ‘*Asistencialismo*’ may be linked to paternalistic attitudes in clinical settings, thereby challenging preconceived ideas about autonomy and individual choice that are the pillars of biomedical ethics. As I previously noted, the main peril the CPE foresaw about the implementation of a service such as the healthcare van was its contribution to the perpetuation of the social exclusion of the population by fomenting their dependency instead of their autonomy. The CPE’s reasoning is grounded in the ideas of choice and autonomy that are connected to the notion of citizens as active and independent actors (Mol 2008). In this way of reasoning, those who live in the settlement are there as a consequence of their own choices and therefore, they are responsible for their social exclusion. It is through these suppositions that the CPE understands the settlement dwellers; therefore, providing care at the settlement entails dependency. Consequently, the nurse’s stance defending the correctness of providing care in the settlement is close to that of those CPE members that supported the healthcare van’s creation as a matter of social justice. But still, defending the rightness of providing care at the settlement regardless of entitlement status (or quota of legitimacy) challenges the CPE’s assumption that any intervention should aim to eradicate the settlement.

‘*Asistencialismo*’ represents not only the materialization of the risk of dependency, but has special connotations for the different members of the CPE. ‘Providing care’ (“*dar asistencia*”) is the main task in clinical settings and it does not entail a negative connotation as long as it is not connected to paternalistic attitudes or positive discrimination. However, in the context of social work, assistance-focused orientations are connected with old-fashioned representations of their role (the archetypal ‘Catholic ladies’ during the Francoist regime), a role which was organized around the relief and moral control of the poor (Ioakimidis, Santos, and Herrero 2014) instead of promoting structural changes. For social workers at the CPE,

---

<sup>96</sup> *Asistencialismo* is not included in the RAE or the Maria Moliner Dictionary. The Oxford Language Dictionary defines *asistencialismo* as “Actitud política orientada a resolver problemas sociales a partir de la asistencia externa en lugar de generar soluciones estructurales” (political attitude oriented to addressing social problems by giving assistance instead of promoting structural changes)

*“asistencialismo”* is an evil to be avoided and interventions with settlement dwellers should be framed in terms of progress and development. As one social worker told me, ‘If there is not an improvement plan with the family, we are not able to grant emergency aid, no matter how desperate the situation is’<sup>97</sup>.

For the van’s workers, providing care is a goal in and of itself and also a means to help their patients achieve more autonomy. The van’s physician put it in these terms: ‘When someone comes to the van with a minor problem that you can solve, it is great because they will come back with other problems and begin trusting you’<sup>98</sup>. For her, the opportunity to establish a trusting relationship out of providing care when people approach the van is crucial to her work. Even if it is an apparently insignificant health problem, the physician and nurse tend to address it carefully, especially when the patient is new to the van. Gaining autonomy, for the van’s physician and nurse, is not about making informed choices and decisions about health problems. They frame the achievement of autonomy as the process through which the settlement’s inhabitants become able to demand their rights, be it at the admission desk, in the consulting rooms, or at the employment office. For the van and the nurse, gaining autonomy revolves around becoming a citizen with full rights and being able to exercise those rights. However, the nurse and physician acknowledge that in the process of gaining autonomy, patients need assistance and support and they include this support as an ordinary work task. They perceive autonomy not as a fixed goal but as a process in which there are different steps to be taken. In the interview, the nurse made mention of this connection between autonomy and citizenship as one of the pragmatic objectives of the van’s workers during the first years: ‘Do you remember? The first year we never stopped telling ourselves, the goal is to stop the begging tone when they come to the van... they feel that it is their right and not charity’<sup>99</sup>. This reformulation of the van’s objectives reflects on how the van’s workers understand their work as a

---

<sup>97</sup> Si no hay un plan para mejorar las condiciones de la familia no podemos darles la ayuda de emergencia, independientemente de que sea una situación desesperada’

<sup>98</sup> ‘Lo mejor es cuando vienen con una tontada que puedes resolver, así te aseguras la confianza y volverán con otros problemas’

<sup>99</sup> Acuerdate que nos pasamos el primer año repitiendo que el objetivo era que no vivieran a la furgoneta como a pedir limosna... que era su derecho y no caridad’

means to help the settlement dwellers to achieve full citizenship. Furthermore, the emphasis the nurse makes in his statement on changing the “begging tone” stresses the shift from the compassionate response of humanitarian government to a framework of the recognition of rights.

It is this understanding of autonomy and care that makes the van’s work extraordinary, in the sense that healthcare is provided in unexpected or surprising ways. As the van is the only service of its kind and it was not designed following any intervention model, the physician and nurse built on their knowledge and experience as primary healthcare workers and adapted them to the context of the van. In his research in an mental healthcare outreach agency, Paul Brodwin notes how in the absence of disciplinary knowledge or detailed instructions, frontline workers resort to pragmatic innovation and create a new type of mental health service on the ground (Brodwin 2017). This ‘pragmatic innovation’ that Brodwin refers to is one of the pillars of the work in the van, influencing both the way they organize their everyday duties and the different strategies the physician and nurse develop to provide care. The van’s workers resort to any available resource at hand in order to attune them to people’s needs. Continuous improvisation accompanies the reproduction of formulas that have worked out previously, addressing both patients and professional requirements. The way the van’s physician and nurse organize their work has some of the attributes of what Annemarie Mol calls ‘doctoring’: ‘in doctoring, management and implementation go together, attuning technologies to daily habits, and people’s skills and propensities’ (2008, 91). ‘Pragmatic innovation’ becomes not only a means to provide suitable care to the population of the settlement, but it also frees the physician and nurse from the constraints of the organization of work at the healthcare centre. The next quote from an informal conversation with the van’s physician (whose permanent position is at the healthcare centre) illustrates this point:

‘The good thing about the van is that it is you who organizes (the work) and not the institution. At the healthcare centre they (patients) come and you have to see them no matter what. You have your agenda all scheduled and you cannot decide over it. At the van it is you who organizes the agenda, regardless of the institutional six-minute slots. There, you can be yourself because at the consulting room, it is not you, it is the institution that determines the way you treat people’.



In this quote, the physician reflects upon the opportunities that working in an interstitial service such as the van provides. For her, the van's position in the institutional margins makes it possible for management and implementation to go together (as in Mol's doctoring) and that both management and implementation respond to the situated professional needs and not the institutional ones. The physician describes the van's work as a means to escape from the constraints of the institutional logic that, for her, ultimately determines the way care is provided. Therefore, the van's work, as perceived by the van's workers, does not only entail providing assistance for the settlement dwellers to gain autonomy, but it also makes it possible for the physician and nurse to be more autonomous in their practice. The van's work is extraordinary because care is provided in unexpected ways: by bypassing the organizational constraints and with enough freedom for 'doctoring' (Mol 2008).

Both the physician and the nurse value the freedom from institutional norms in the organization of the daily agenda. However, this freedom has a counterpart regarding responsibility: being responsible for distributing a limited resource (such as the van's services) in a fair way. In what follows I analyse how this distribution takes place as 'doctoring' practices in the van: first, I look at the way they organize their daily work to accommodate the settlement's 'chronic emergency' and how they incorporate some of the admission desk's tasks into their ordinary practice. Secondly, I look at the van's workers' mediation work in obtaining healthcare cards for the settlement inhabitants and how the physician and nurse frame their help in dealing with bureaucratic hurdles as caring for their patients. Finally, I analyse the practices of the van's workers and their relations with other healthcare services in order to understand how cultural difference is enacted in their practices.

## **2.2 Planned Improvisation**

The van does not have a system of previously scheduled appointments in the proper sense; there are some appointments that are orally arranged when some planning is needed, such as scheduled blood tests, for example, because the samples have to be taken to the hospital, as previously illustrated in the extract from my field diary. When a patient phones asking for an appointment, the reasons for her call are discussed on the phone and if necessary an appointment is arranged with an open indication about

the time and place of the consultation. On the phone, once it is clear that it is not an emergency, the team tries to find a convenient time for both parties. Sometimes it is difficult to negotiate this kind of appointments, as the van team rarely gives an exact time for the appointment; they prefer to leave it open as they acknowledge that it is impossible to be precise in their timing.

Without a “list of patients” scheduled for the day, the notebook agenda serves as the template to organise the van’s working hours. There are three main things noted in the notebook: important appointments of patients at the hospital, scheduled blood tests and the quarterly contraceptive injection for women who use that birth control method. This contraceptive injection is provided free of charge at the van every three months and the date of the next scheduled injection is noted in the agenda. Usually the reminder is placed two or three days before the due date, so the van’s workers have some time to remind the patient about the injection in advance and to plan another option if something unexpected happens. Both the nurse and the physician in the van frequently resort to these strategies of writing reminders in the notebook on previous days instead of the actual day, reminders that reflect on their acknowledgment that the appointments are uncertain and flexibility is essential in their ordinary clinical practices. I have just exceptionally seen other physicians or nurses recurring to this strategy of previous reminders: at the healthcare centre they rely on the patient coming at the scheduled time and if not, it is in the patient’s interest to come. One example of the flexibility that working at the van entails is the following compilation of field notes.

‘Like every morning, the van’s workers are getting the necessary equipment at the healthcare centre to begin the day. Once the vaccines are put in the van’s fridge and the paperwork sorted out (printing blood test results, referrals to specialists, healthcare card papers...) we are ready to go. First stop is the coffee shop next to the pharmacy, where the driver goes to get some treatments while the nurse, the physician and I discuss how to organize the morning over a coffee. Looking at the annotations for the day in the notebook, we decide to go first to the “henhouse”<sup>100</sup> as there are some children

---

<sup>100</sup> The ‘henhouse’ is a small settlement where all the shacks are close to each other. It is divided into three different areas because of the orography of the territory but the extension is around eight

with respiratory infections to follow up, a newborn to weigh and some women who are due for their quarterly contraceptive injection. When we arrive in the settlement the first ones to approach the van are three women who were on their way to the fountain. They say hi; one asks for some paracetamol (which I already have in my pocket and give to her); another one, Maura, asks about a referral appointment processed some time ago and, climbing into the van, asks the nurse to measure her blood pressure. The nurse tells her to wait a little bit while we go and look for someone. Maura is not happy with the answer: 'You always make me get out of the van, I always have to wait'. The nurse keeps on walking and tells her to wait again. Maura looks at me and says in an angry-joking tone, 'This Jaime does not like me, he always makes me wait.' I reply that we will be back soon and that she can have a seat and I will measure her blood pressure when we come back but that she should look after the van. Outside it is not very cold but a little bit windy and it is not comfortable to wait. We go to look for the children we wanted to follow up on and on the way to the first house people stop us: Constantin asks for the healthcare card again; he does not have a valid residence permit so there is little we can do; Jaime, the nurse, tells him that there is no news, that without the residence permit there is nothing we can do. Jaime tells Constantin if he is feeling sick or needs something he can come to the van. 'I need a healthcare card, you have done it for all the others but you do not want to give me one'. Jaime tells him again about the process: 'Look Constantin, I would be more than pleased to give you a healthcare card, but I can't do it without the residence permit. Try to find a way to get one; speak with Carlos (the outreach educator)'. Constantin is not happy and continues on his way, nodding to himself. While Constantin was talking to Juan, Helena approached us and now she asks us to go to her house and see one of her daughters who is sick. I tell her to bring her to the van, but she replies that that there are always a lot of people and that she does not want to wait in the cold with a sick child. I try to convince her to come to the van by telling her that she will have some priority. Meanwhile, Carmen, the physician, has gone to the house of one of the women who is due for the quarterly contraceptive to tell her to come; she comes back to where the nurse

---

hundred square kilometers so you can walk from one house to another easily. The van usually parks at the entrance of the settlement, next to the road and close to the fountain.

and I are and informs us that the woman is already at the van. She saw that there were a lot of people around waiting so it would be better to go back and afterwards go and look for the people we planned to visit.

Back at the van, there are around fifteen people waiting, most of them women, some of them with children in their arms. When we were approaching, they come to us stating out loud, everybody at the same time, the reason why they are there: 'Jaime, you have to look at my baby, he has been coughing the whole night' 'I am first, I arrived before the others, I have been waiting.' 'I just came to measure my blood pressure, it is just one second.' 'Carmen, I feel very bad, I need you to examine me very well, I have a big problem I think.' 'Give me a cup.' 'She is pregnant again!! She is pregnant again!' These are just some of the things I heard, apart from some talking in Romani taking place at the same time among the patients. Some women are silently waiting and just looking at us.

We open the van's rear door and find Maura sitting and waiting for us, I decide to go and measure her blood pressure to make space for other people to come in. In the meantime, three women have already got into the van with their babies and placed them on the examining table. Jaime complains because there is no place to move and 'If they are sick they are going to pass it to each other; it is better that you wait outside'. They do not want to get out because they think they will lose their turn. Carmen is already examining one of the babies; I am done with Maura whose blood pressure is fine and trying to get her out of the van but she can't reach the rear door because there is no space to pass by... finally Jaime gets out and manages to make some space for Maura to get out. Outside there are more people, Jaime is giving some plastic cups to some women who want to have a pregnancy test and asking each one of the people who are waiting what they need: 'is your son eighteen months old already? If you want you can bring him and we can vaccinate him; fetch him and your family book so we take a picture in order to make the healthcare cards for the little one, and can I ask you for a favour? You have good relations with Raluca, right? Would you mind asking her to come in with her son? She knows, we told her we would be here today but maybe she has not seen the van'. Carmen is done with examining another child but the mother needs a pregnancy test so she gets out of the van with a plastic cup; the baby is still on the examining table, so I take care of him while Jaime tells someone else to come into the van and Carmen takes

care of the new patient. Some women come and knock on the side window. Making hand signals, they ask me to open the window. Holding the baby I open the window and the women pass the plastic cups with the urine to me for the pregnancy tests. One of them tells me not to tell anybody: 'You just tell me in four eyes, do not show anybody'. I have neither free hands nor protective gloves to take the cups so I go to the back door to see if the mother of the baby is back and give her the baby and to get some gloves, too. Freed of the baby and with a new cup full of urine I move to the front to take care of the other two pregnancy tests. Carmen is examining one toddler at the back of the van, Jaime is down next to the back door organizing who is next and stopping people from popping into the van, the phone is ringing but nobody is free to answer. I will call back while waiting for the pregnancy tests results.

This account of the van's work is made out of a compilation from my field notes to give as faithful a description as possible of how the van's workers organize their work. The account is made up of notes from different days in the van because –as I aimed to show in the account- I was required to participate and help the nurse and the physician due to the need to quickly accommodate the patients' requests<sup>101</sup>. Some patients approached me directly and depending on their demand, I referred them to Carmen, the physician or solved it by myself. This is the reason why I found it extremely difficult to take notes on everything happening at the same time during the same day. I barely found time to write some short notes on my phone and elaborate from them after the consultation. My intention with this compilation of field notes is to give an idea of the business and sense of urgency that reigns in the healthcare van and the creative strategies the nurse and physician deploy to adapt to it with planned improvisation, something that would be difficult to show without gathering the notes together.

From a superficial reading, the account I give seems to portray the settlement (and the provision of healthcare there) as something chaotic and without order. This description may be read as flawed with the pernicious premises used to described the

---

<sup>101</sup> As most of the patients knew me from my previous (and later) work as a physician in the van, it would not make sense that I not collaborate and just remain as an observer while my colleagues were so busy.

ghetto (or marginal areas in the city) ‘as seen from outside and above’ (Wacquant 1997), especially with the tendency to describe the ghetto with the ‘trope of disorganization’(1997, 344). My aim is just the opposite: my objective is to identify the principles that underlie the organization of the settlement. The way to do so is through the investigation of the different ways the van’s workers attune their practice to the order and functioning of the people living in the settlement. However, I would not like to cast aside the idea of disorder, as it is useful to understand the meaning given to the van’s practices at the healthcare centre. From the healthcare centre, the colleagues of the van’s physician and nurse describe the van’s practice as disorganized and messy. They ground this assertion on the lack of a register of their activities in the van in the electronic clinical records of their patients, a complaint that is partially right. The next quote illustrates this point; it is from one physician in one of the regular team meetings at the healthcare centre:

‘I know what you do and the patients know what you do but there is nothing noted down in the clinical records, so at the end of the day I do not know if the patient is making things up or I am misinterpreting and it leads to a misuse of the system<sup>102</sup>’.

As the van’s workers do not have a computer in the van, they register the most significant clinical facts on paper records organized in family folders. Vaccination, referrals and blood tests are registered in the electronic clinical records, as well as some prescriptions and chronic diagnoses. The van’s physician and nurse do not systematically write every consultation in the electronic clinical records because it would be incompatible with providing care and being present in the settlement: it would take up a lot of the consultation time and keep them at the healthcare centre to use the computer there. Still, the ‘disorder’ in keeping the electronic clinical records up to date is not something specific to the van’s workers, as it was one of the recurring topics at the staff meetings in both healthcare centres. Physicians and nurses find it difficult to keep the different protocols updated when they have a patient allocated every six minutes. However, in the case of the van’s workers, it is explained not as an

---

<sup>102</sup> ‘Yo sé lo que hacéis y los pacientes saben lo que hacéis pero no hay nada escrito en la historia, así que al final yo no sé si el paciente se lo está inventando, si yo lo estoy entendiendo mal y vamos, que al final esto lleva a un abuso del sistema’

inadequacy of time allocation or the registry method, but as a consequence of a disorganized practice that leads to misusing the system.

Curiously, this idea of disorganized practices was similarly used to refer to the clinical practice of the physician who attended to most of the Gitano population at one of the primary healthcare centres, like in this quote from one of the administrative staff :

‘Problems as such, we do not have here (with Gitanos) because we have a physician who has most of the Gitano population assigned to his agenda, because of word of mouth [...] but them (Gitanos) they use the public healthcare system a lot, and they misuse it, I tell you again that I am sure that they misuse the healthcare system because here we have a physician that consents to everything<sup>103</sup>.

In this case, the problem (despite the insistence in not having problems when providing healthcare to Gitanos) was not only that the physician was “spoiling” the patients but also that it had repercussions in the organization of the healthcare centre work, as the next quote shows:

‘Actually, when he is on holidays the rest of his colleagues have agreed to prioritize a locum for his consultation, because it is chaotic if he is not there’<sup>104</sup>.

Both cases illustrate how those healthcare workers that are identified as attending to Gitanos and Roma, be it in the settlement or at the healthcare centre, are perceived as ‘disorganized’ or at least as participating in and contributing to the messiness of their patients. Sarrandon-Eck, Farnarier and Hymans (2014) describe a similar process among healthcare workers from an psychiatric outreach team in Paris, where the positions in the hospital hierarchy and their status was contested by other colleagues working at the same public hospital. They describe this phenomenon as ‘a form of symbolic contagion from the stigma (Goffman 1974) that surrounds the

---

<sup>103</sup> ‘Problemas como tal no tenemos porque tenemos un médico que es en el que casi toda la población gitana del centro está asignada a él porque de boca en boca [...] pero ellos utilizan muchísimo la sanidad pública, y la utilizan mal, te vuelvo a repetir que estoy convencida que la utilizan mal porque aquí hay un médico que les permite todo’

<sup>104</sup> ‘De hecho cuando se coge las vacaciones todos los demás compañeros han dicho que tiene que haber suplente para su consulta, porque es que es caótico cuando falta él’.

homeless people they look after' (Sarradon-Eck, Farnarier, and Hymans 2014, 259). In the case of the van's workers and the physician preferred by Gitanos, what is questioned is their willingness to participate in a way of organizing the healthcare provision that nevertheless is challenged by most of the healthcare workers. The difference comes from the premises on which healthcare workers ground this contestation: in the case of the van's workers and the Gitanos' physician they place the problem in the Gitanos' misuse of the healthcare system whereas for the rest of the healthcare workers the problem is the inadequacy of the institution to organize the provision of care. It is because of this phenomenon of 'contagion of the stigma' that surrounds the Gitanos and Roma that I refrained from describing the van's work as 'organized disorder' as was initially my intention (to avoid building on the negative representation and stigmatization of the Gitano and Roma population) and opted to use 'planned improvisation'.

### **Where private and public go together**

To begin with the analysis of the different ways the allocation of healthcare is organised in the van, it is interesting to explore the space where this care is provided. The van is divided in two spaces: the front compartment which is just used during the drive, and the back, which is where most of the activities take place. The back tends to emulate a regular consulting room at the healthcare centre and is divided into two different spaces: at the front there is a small space where boxes with the clinical records organized in family folders are stored next to a small desk with two chairs. The back area resembles the examination space in the consulting room, equipped with an examining table and similar medical equipment to the healthcare centre. The front door that leads to the front area with the table has been broken since the beginning and therefore the only way to access the van is the rear door. There is no waiting room and people either stand outside or if there is enough place, in the van. When it is cold or raining, the van is at full capacity and no place for privacy can be found. Despite the design's original purpose to recreate a standard consulting room, at the settlement the different spaces in the van are used to meet the people's needs. The patient's expected itinerary from the clinical records desk to private examination table rarely takes place in the van. Similarly, consultations seldom take place in the same terms of privacy as at the healthcare centre: frequently there are other people in the van while the physician is asking questions, notably if the patient is a child. The



example of various children of different ages lying on the examining table given in the account is routine.

That the van is not a place characterised by privacy is acknowledged both by the van's workers and patients. As shown in the previous field notes extract, one of the women who came to take a pregnancy test explicitly told me to 'tell her the result with four eyes'<sup>105</sup>; that was her way to tell me both to keep the result of the test confidential and to hide the test from nosy looks. Hence this woman showed that she was aware that privacy and sometimes confidentiality are not a given in the healthcare van, but have to be sought. Privacy is pursued in different ways and the nurse and physician have different resources to provide that privacy. Looking back at the initial account of a working day in the van, Nuria's case is a good example of one of these strategies to gain privacy. Nuria sought out the van to take a pregnancy test that was positive and as at that moment it was impossible to discuss the different options she had in the van privately, I arranged to phone her afterwards. Calling the patient back to discuss private issues is a recurring strategy that the van's workers use. In doing so, they manage to guarantee confidentiality by using the time it takes to drive to another area of the settlement to give confidential advice on the phone.

The conflation of public and private in the van is also connected to the blending of the admission desk and the consulting room in the same space. The disclosure of information that takes place at the admission desk when at the healthcare centre, in the van is directly revealed to the physician or the nurse. Both of them are responsible for organising the order in which people are attended and they take turns, depending on how busy each of them is. Looking back at the field notes account, as the physician had three babies to examine, it was the nurse who was organising the "waiting list", but it would be the opposite if the nurse was vaccinating a child or taking care of a wound. Physician and nurse are flexible in performing the task of triaging patients. Triage is a term frequently used in biomedical contexts to refer to the assessments of

---

<sup>105</sup> This expression "with four eyes" is used to make clear that the information would be disclose only to the person and nobody else would be around.

patients to prioritize those who need attention urgently, but triage can be deployed to different ends depending on the criteria the assessment is based on (Nguyen 2010).<sup>106</sup>

Ultimately, triage is a means to allocate clinical care by optimising scarce resources based on different criteria. The field note compilation shows how the van's workers do not allocate clinical care on a 'first come-first served' basis; instead, they assess the patients' needs to establish priorities. Nonetheless the assessment is done differently from an emergency room, as the priority is not only based on urgency. At the van, triage has a double function: first, it serves to accommodate the immediacy in being attended that patients ask for, and not to make them wait for something that can be easily solved (see the example of the woman asking for some paracetamol in the field notes). Secondly, the nurse and physician use triage to challenge the hierarchies established at the settlement that give priority to some people over others and that would place some people in a difficult position to approach the physician and nurse. So triage is not deployed based only on strict biomedical criteria, but also on the longstanding knowledge that the physician and nurse have of the dynamics and organization of the settlement dwellers.

About this double function of triage, both to adjust to the patients' need for immediacy but also to revert some of the hierarchical relations- perceived by the physician and nurse as unfair- the van's nurse told me in an informal conversation,

‘That is the most difficult part, to be careful not to overlook something important because there are some people who cry more than others, and those who remain silent risk remaining unnoticed. You have to always be alert’<sup>107</sup>.

Unlike the healthcare centre, where a pre-established agenda is followed and the waiting room is not a concern for physicians and nurses (if there is not an emergency), in the van the nurse and the physician take an active role in organizing the agenda

---

<sup>106</sup> In anthropology the term has been notably used by Vin Kim Nguyen (2010) to describe the procedures put in place in West Africa to determine who should have access to HIV treatment.

<sup>107</sup> ‘Es lo más difícil, tener cuidado para que no se te escape algo importante porque como hay quien grita más que otros, los que esperan callados pueden pasar desapercibidos. Tienes que estar siempre alerta’

and the “waiting area” becomes a space where clinical principles are intertwined with the social organization. The physician explained this point to me:

‘I understand that going to the doctor is not a priority in the settlement, that if they have to wait a lot their children are alone... there is the fear of not being attended that I think also influences the immediacy with which they want to be treated...I mean, here they live in this state of chronic emergency and we have to adapt to that in our work, and little by little they become more flexible with us, too, and wait if we ask them to<sup>108</sup>’.

The physician acknowledges the difficulties that the people in the settlement face in their everyday life and understands that it is the van’s workers who need to adapt their work to accommodate the way of functioning in the settlement. Furthermore, she perceives this process as bidirectional, admitting that the patients also adapt to the van’s workers’ demands. Unlike the admission desk and the consulting room at the healthcare centre, in the van the physician does not interpret immediacy in cultural terms, but as an adaptation to the living conditions in the settlement (*‘state of chronic emergency’*). Both physician and nurse believe that longitudinality (the presence and use of a regular source of care over time that I discuss in the consulting room chapter) becomes crucial in the van to do correct triage and to keep important health issues from being overlooked. In the conversation the nurse brings up a case that illustrates this point:

‘Remember the other day, with Nacu, it was at least two years since he had come to the van and then he comes with his pregnant daughter when she was having a gestational diabetes test. And he was complaining about that pain in his shoulder, very mechanical and all that but then you (referring to Carmen, the physician) asked him about his heart condition and the treatment he had to follow... and he ended up in the emergency room... because the shoulder pain was the most important for him but you took advantage of that to make him go back to his heart medication and back to the cardiologist, and tried to prevent a sudden death due to his condition... somewhere else, they would

---

<sup>108</sup> ‘entiendo que la prioridad en el poblado no sea ir al medico, que mientras esperan los niños están solos ... y que el miedo a que no les atiendan también influye la inmediatez con la que quieren ser atendidos... si es que viven en una emergencia crónica y nos tenemos que adaptar a eso para hacer nuestro trabajo. Aunque poco a poco ellos también esperan más si les pides que lo hagan’

give him ibuprofen for the shoulder pain and that's all; actually, that is what they did at the emergency room!'

In this quote, the nurse is making a reference both to the importance of longitudinality to provide adequate care instead of just treating symptoms and also to the way the physician and nurse are concerned with the health problems of their patients, going beyond the actual reason for the consultation and bringing the biographical account to the front. This repertoire of practice is not specific to the van and I have already described another example of this biographical approach in the consulting room at the healthcare centre (Azucena's vignette). However, bearing in mind the barriers to accessing services that settlement inhabitants encounter, the closeness and concern shown by the nurse and the physician become crucial to being able to provide quality care. In the next section I will further delve into Nacu's story and the physician and nurse's advocacy for their patients in other healthcare facilities.

For the van's physician and nurse, flexibility and being able to improvise is understood as a necessary attribute of their work: they acknowledge the precarious living conditions in the settlement (as shown in the previous physician's quote) and they do not prioritize complying with schedules and appointments over providing assistance and care. Furthermore, they understand that this flexibility to change plans and improvisation is necessary to approach everybody, even those who are at the bottom of the settlement hierarchies. The physician and nurse resort to the trusting relationship they have built over the years to equitably distribute a limited resource such as their work. Improvisation is planned over this longstanding knowledge of the people they attend to and the accumulated experience gained over the years practicing 'pragmatic innovation' in the van. Nevertheless, this planned improvisation is not free of tensions and, as resources are limited, sometimes the van's team are blamed for there not being enough time at one spot or another, or for giving special treatment to certain areas of the settlement over others. The van's nurse takes this as a side effect of working in a context of severe deprivation where the population fights against each other to gain access to limited resources; he suggests that having scheduled stops would not change the perception of unequal treatment. As the nurse put it,

'We considered having fixed, scheduled stops in different areas of the settlement, but we realized that that would constraint our work and we do not

think that it would avoid the “always everything for the others, for me never anything” that surrounds working in such a precarious environment<sup>109</sup>.

The nurse refers to the perception of unequal treatment that the settlement inhabitants frequently put into words. This expression of unfairness mainly takes place when there is a disagreement, as Maura’s example in the field notes illustrates; Maura took it as something personal (‘Jaime does not like me’) when she was asked to wait and referred to unequal treatment (‘he always makes me wait’). However, the nurse does not take it personally and he trusts their criteria to treat everybody equally and to be flexible enough to improvise depending on needs. Furthermore, the nurse assumes that the perception of unequal treatment is produced by the restricted opportunities that settlement dwellers have and the need to compete for scarce resources. Instead of organising their work with a tidy schedule, which could serve as an alibi to show their egalitarianism against the accusations of unfairness, they prefer to maintain their flexibility and explain the reasons why they may neglect one area of the settlement during a period of time or why someone is asked to wait at a specific moment. Planned improvisation is not free of tensions but it is the best pragmatic answer that the physician and nurse have found to address the difficult equity and suitable allocation of care in the settlement. As previously shown, providing universal coverage (reaching the most people possible) is given priority over complying with organizational rules and is the foundation that organises the van’s work. Providing healthcare to the people of the settlement is understood as a fundamental citizen’s right and by framing their work in these terms the physician and the nurse outweigh the limitations that working at the van entails. The recognition of the right to healthcare does not stop at the van: in the next section I address the next step to move from the ‘island of non-citizenship’ to a space of citizenship such as public healthcare centres. For this movement, there is a bureaucratic toll to pay: obtaining a healthcare card.

---

<sup>109</sup> ‘nos planteamos hacer paradas fijas pero al final nos parecía que limitaba mucho nuestro trabajo y que de todas formas no iba a evitar el “para los demás siempre todo y para mi nunca nada” propio del trabajo con gente tan en precario’.

## 2.3 Playing Cards

In the admission desk chapter I already addressed the issue of the different entitlements to healthcare, how these entitlements were granted on the grounds of what I call “quotas of legitimacy” and the difficulties that settlement dwellers encounter to comply with all the requirements in order to be granted a healthcare card. In this section, I address the issue of the healthcare card from a different perspective, that of the van’s workers; to some extent, I incorporate the perspective of the settlement’s inhabitants. For the van’s workers, the healthcare card represents the first step to becoming a citizen with full rights and therefore it is one of their priorities to facilitate the procedure to obtain it.

At the van, giving assistance to settlement inhabitants to obtain healthcare cards has become a routine task. Actually, questions about how to obtain a card or renew an expired one are usually the reason why new patients approach the van first. That people approach a physician or a nurse to obtain a healthcare card seems counter-intuitive at first; still, the news that in the van they give healthcare cards spreads by word of mouth. ‘Are you Jaime? I’m here because they told me that you give out healthcare cards’ is an example of the reasons why people approach the van in the first place. Usually, the patients ask for the nurse as the person in charge of dealing with the procedure, and because he has been working in the van uninterruptedly since the beginning. Therefore, for the settlement dwellers it is the nurse who has the key to obtaining a healthcare card and to entering a space of citizenship. The healthcare card, like other official documents that grant access to rights, represents different things simultaneously. Some authors have already signalled the ‘almost magical virtue of social integration’ (Fassin, Morice, and Quiminal 1997) residence permits are endowed with, how these permits become fetishized (Suárez Navaz 1999) or the ‘repository of their dreams of citizenship’ that the residency permit represents (Giordano 2014). To some extent, the healthcare card (as a key document to access one of the fundamental rights granted to citizens) comes to embody the possibility of social inclusion. This representation is shared by both the van’s workers and the settlement dwellers and that is the reason why assisting in the procedure is prioritized. The interest that settlement dwellers show in obtaining a healthcare card challenges the representation that portrays them as passive subjects not willing to integrate and not complying with the norms. Furthermore, the fact that settlement dwellers seek

assistance in the van to obtain healthcare cards (that ultimately would grant them access to healthcare in a “normalized” healthcare facility) shows that assistance-focused services are not at odds with inclusion.

The van’s workers have creatively adapted to the different changes in the legislation over the years. During the first years in the van, we gathered personal identification documents and photocopied them, filled out forms and brought them to the welfare office. At that time we reached an agreement with the welfare office manager and we were allowed to apply for children’s social security numbers (one of the requisites to getting a healthcare card) by bringing the application and documents to the office ourselves. This agreement facilitated the process and saved the children’s parents a trip to the welfare office. At some point, the legislation changed and it was no longer possible to apply on behalf of the children’s parents so we needed to change the strategy. Looking back at that period, I find there is a remarkable paradox in the ease with which people trusted us with very valuable documents -such as family books and identity cards- and the alleged mistrust by the socially-excluded population of institutions and their representatives. For several years, every time a baby was born or a new child came to the settlement, we took the documents with us back to the healthcare centre to photocopy them and bring them back the next day (or sometimes two or three days afterwards). I just remember one or two cases of people who preferred to make the copies by themselves.

During the time of my fieldwork, the process was simplified by technological means, as it was enough to take a picture with one of our phones and send it by email to the administrative clerk who processes the documents. However, as access to healthcare was curtailed for those who did not have a valid residence permit (BOE 2012), it became impossible to obtain healthcare cards for those adults that had not regularized their legal status. In the field notes compilation there is one example of what in Spanish healthcare contexts was called “*la exclusión sanitaria*” (exclusion from healthcare). Constantin, like many others who did not have a residence permit, came to ask us about how to get a healthcare card, but the nurse had to admit to him that it was unfeasible, while inviting Constantin to come to the van if he was not feeling well. Still, Constantin was not seeking care; what he was asking for was to be able to have the document that entitled him to access healthcare: he was seeking rights, and for him the healthcare card came to represent his status as a citizen.



Figure 7. The document bag

The healthcare card is, for the settlement dwellers, one of many important documents to take care of, along with identity cards and other legal documents such as council registers or residency permits, and so on. Most of these documents are difficult to obtain, some of them are expensive (for example getting a duplicate passport at the Romanian consulate costed around one hundred euros at the time of my fieldwork) and others are just valuable because they prove encounters with different institutional actors (like proof of appointments at the hospital or at social services, proof of benefit claims, etc.). For one reason or another, all these documents are considered special and endowed with more value than other material belongings. Because these documents are important and the first thing to save in case the settlement dwellers need to flee from their makeshift house (in case of fire, eviction...), in most of the shacks at the settlement these documents are gathered in a bag that hangs close to the front door. Hanging the bag high from the floor and next to the door is a way to protect these documents from children and to have them at hand in case of emergency. The document bag ends up representing the precariousness of living in the settlement and how the settlement inhabitants cope with this 'state of chronic emergency' (as the physician put it) they live in. Furthermore, the document bag shows what is valuable to save, and in this case it is those documents that are linked with different facets of being a citizen; therefore the document bag becomes a 'repository of their dreams of citizenship' (Giordano 2014).



Another document that the van's workers needed to sort out to process healthcare cards was a valid proof of address to resolve the lack of registry at the council office (*empadronamiento*). Grounded in their status as public employees (which share some characteristics with civil servants) the van's workers claimed that they were as able to legitimately certify the place of residence as a council worker. The law established that any civil servant can certify the place of residence but there was no mention of public employees. However, they found another legal document that legally equates both categories (civil servants and public employees) as able to provide certificates. The van's workers took advantage of that loophole to make their claim, which ultimately was accepted. With this last obstacle surmounted, the van's workers were able to gather the documentation needed to apply for healthcare cards for the settlement inhabitants, except for those who did not have a valid residence permit (that were more than just a few cases). However, all this work of mediation and document gathering would be futile if there were not an administrative clerk at the healthcare centre willing to process the healthcare card petitions (and to turn a blind eye to some of the inaccuracies presented).

Being able to facilitate the process to obtain healthcare cards is a meaningful task for the van's workers for two reasons: first, it is the necessary condition for granting the right to access healthcare, which for the van's workers is the first step to becoming a full citizen. Secondly, facilitating the process to obtain a valuable document such as the healthcare card is a means to establish a trusting relationship and to be able to reach more people, and to be approachable, too. Therefore, despite the fact that the bureaucratic hurdles of gathering all the documents to process the healthcare card exceeds the limits of the nurse and physician's professional role, they consider it like any other act of care for the patients. To some extent, processing the healthcare card helps the van's workers cope with the feelings of futility, as this quote from an interview with the nurse shows:

‘I do not know if we are contributing to ameliorating the health conditions of the people, but at least they manage to have the healthcare card and feel that they can go to the hospital if they need to’.

In this quote, the nurse questions the impact of their work on the health status of the settlement dwellers but his doubts are outweighed by their assistance in issuing healthcare cards.

The way the physician and nurse broaden the realm of their activities to include and prioritize the assistance in obtaining healthcare cards shows the kind of adjustment of technologies and practices to patients' needs that characterise good care (Mol 2008:91). To obtain healthcare cards, the van's workers tinker with the resources, technologies and infrastructures available to them, re-signifying their professional role as physician and nurse. They take care of precious documents for the settlement dwellers that entrusted these documents to them in order to obtain another valuable document. So far it is evident that the procedure to obtain a healthcare card is valuable for both the settlement dwellers and the van's workers, but for the latter it has an extra value I have not mentioned yet. Providing patients with a healthcare card enables the van's workers to refer those patients who need specialized care and to give subsidized prescriptions to those patients with chronic diseases. Without a healthcare card, these referrals and prescriptions are not possible, placing the nurse and the physician in the difficult position of knowing what the patient needs but not being able to provide it to her. But, as I will explore in the next section, having a healthcare card does not always make healthcare fully accessible, even with the mediation of the van's workers.

## **2.4 (Trans)Positions Of Citizenship**

To begin this section I would like to recall one of the ethnographic vignettes from the admission desk. In the vignette one patient from the settlement was asking for an appointment for that day to get some prescriptions for her asthma crisis. She did not manage to get an appointment and the van's physician wrote the prescription for her. The vignette ends with this commentary from the nurse when I told him what happened: 'You see, we are supposed to be a bridge between the settlement and the clinic, and when we succeed in bringing people into the clinic, they do not accept them. There is no room for them at the clinic'. I recall this quote because it nicely illustrates how the van's workers differentiate their practice from those enacted in primary healthcare and the difficulties they face to successfully "integrate" their patients in the "normalized" healthcare network. However, the nurse does not refer to the patient's cultural difference as the problem that impedes access to healthcare, as was argued in the CPE report. Instead, the nurse refers to the primary healthcare centre's 'lack of room' for patients from the settlement. In what follows I explore how the van's workers understand their work with regards to the regular healthcare

facilities they work with and the difficulties they face when accompanying people from the settlement to these services.

As the quote shows, the van's workers tend to question the capacity of the healthcare institution to accommodate what they refer to as the "cultural difference" of the patients that come from the settlement. In the subsequent examples, I show how either because of the organizational logic that clashes with the patient's needs or because the primary healthcare centre is already saturated, the van's workers find it difficult to help their patients in the process of receiving adequate care. The van's nurse and physician seldom use the idiom of cultural difference when talking about their practices, but instead tend to use the idiom of institutional logic to refer to the practices that reproduce the exclusion of settlement inhabitants when they go to healthcare facilities. For the van's physician, the exclusion of the van's inhabitants is due in part to the standardization produced by providing care through protocols and to the institutional management of appointments and time. Referring to the prenatal care program, the physician questions how it is organised and how it fails to adequately meet the needs of the settlement patients:

'You have to go one day to take a blood test, another day to the ultrasound scan, another to talk with that man (referring to the gynaecologist)... maybe that day he does not refer you to the next... so a new appointment... to take six really necessary tests it takes up a lot of your time (patient)...that is real, I felt like that (when she was pregnant) was a waste of time. But then, you go with Ana, I am telling you (referring to the gynaecologist) Hello! She had a C-section six months ago and he LUMPED HER TOGETHER WITH THE REGULAR PREGANCIES! Sixteen years old, you know... ok, maybe it has to be like this but...'110.

In this quote the physician is questioning the ability of the organization to be flexible and accommodate patients who have different needs from the "standard" population defined in the prenatal care protocol. She does not only question whose needs the

---

<sup>110</sup> Es que tienes que ir un día a hacerte la analítica otro día a hacerte la eco, otro día a hablar con el señor, ese día a lo mejor no te pide la siguiente... quedas para otro día...para seis cosas que son super necesarias realmente requiere mucho tiempo, Sabes? Que es real, que yo lo vivía como una perdida de tiempo aparte.. Pero que luego vas con Ana que te estoy diciendo hola! Tiene una cesárea hecha de diciembre y la mete en el mismo saco! 16 años sabes? Pues bueno, vale pues tendrá que ser así, va

current organization of prenatal care responds to (which for her seems to be institutional needs) but also its potential to gloss over important health differences that may need specific attention. Beyond the organizational value of the protocol, the physician questions its effectiveness; the protocol is based on a rationale that prioritizes objectivity and leaves out the patient's complex stories (as was Ana's case). Following the objectivity discourse, patients' lives and their complexities 'are cast as a distracting disturbance. They are taken to be sign of the messiness of mundane practices that fail to submit to theoretical ideals' (Mol 2008, 49). Ana's story is cast aside and she is lumped in with the rest of the pregnant women. Ana's new pregnancy after a recent C-section places her in the category of unsanitary citizen (Briggs and Mantini-Briggs 2003) because she has not embraced the modern biomedical paradigm. But still, what the van's physician underlines is the potential of the protocol to reproduce Ana's exclusion from sanitary citizenship even when she aims to embrace it.

In the quote the physician refers to one of the accompaniments to the hospital that the van's workers do with some patients from the settlement. As in the aforementioned case, the van's workers prioritize accompanying patients that they consider as having a serious health condition that will need follow up: Ana was pregnant and had had a recent C-section, which put her at risk of uterine rupture during pregnancy. In some of the cases of serious conditions that may benefit from specialized care, the physician and nurse discuss the benefits of accompanying the patient, both as a way to show support to the patient and to facilitate the follow-up, if possible. The seriousness of the health condition is one of the aspects that they take into account to accompany someone, but also the family or social support that she may have, the degree of awareness about the importance of the condition and her degree of familiarity with the healthcare system structure. Again, the decision to accompany someone is taken not solely on the basis of the "biological" condition but of her biographical account, attending to facts and values together, as Annemarie Mol (2008) describes in those practices informed by the logic of care. In Ana's case, it was both the seriousness of her condition and her lack of family support (which was partially due to their unawareness of her condition) that made the van's workers decide to accompany her to the gynaecologist.

These accompaniments function as a (trans)position of citizenship, as the van's workers literally move the patient from a place where there are no rights to another where they have entitlements. Still, the accompaniment entails some reciprocity, as it is a strategy the physician and nurse deploy to cope with the feelings of futility raised by their practices, as this quote from an interview with the nurse shows:

‘Knowing that someone is suffering from something that can be treated but that for different reasons is not accessible... you cannot stand there without doing anything; it is part of your job’<sup>111</sup>.

Like the expansion of their professional role in order to give assistance to obtain healthcare cards, the accompaniments are reconceptualised as a care practice, too. The accompaniments are part and parcel of the van's work as an ‘interstitial service’ (Lovell 1997) inasmuch as they reflect on the liminal and nomadic character of the van's work. Being at the threshold of the institutional logic enables the van's workers to be adaptable in their practices and to use their mobility not only to reach those populations that are difficult to reach (the socially excluded) but also to help them reach the institutions from where they are excluded.

Despite the accompaniments, the nurse and the physician acknowledge that there is not an effective correlation between the healthcare services and the settlement dwellers' needs, reproducing the mechanisms of social exclusion that the healthcare van is meant to bypass. Therefore, the van's nurse and physician question their work as just being focused on “working with the settlement inhabitants” to fit into the healthcare system. Instead, they conceptualise their work as widening their colleagues' perspectives about the people living in the settlement: to do so, they give special attention to the training they provide while training physicians and nurses to rotate in the van. As the nurse puts it ‘if only they (the interns) manage to question why at the hospital they do the things they do and whose interests they privilege, there is hope they will embrace a different kind of practice’<sup>112</sup>. For the nurse, one of the ways to make sense of the contradictions in his work is to contribute to the training of new

---

<sup>111</sup> ‘saber que alguien tiene algo que es tratable pero que por lo que sea el tratamiento no accede al tratamiento... no te puedes quedar de brazos cruzados, es parte de tu trabajo’

<sup>112</sup> ‘si al menos consiguen cuestionar por que se hacen las cosas en el hospital y a quien favorecen, entonces podemos esperar que trabajen de otra forma’

physicians and nurses so that eventually they will not reproduce the exclusion that takes place at the healthcare centres. Or as one general practitioner resident told me during her rotation at the van: ‘here instead of learning evidence-based medicine, we learn that what works is what-is-available based medicine’<sup>113</sup>. This resident was pointing to the same contradiction the physician referred to when questioning the prenatal protocol: standardized care has difficulties to address the health needs it intends to because standardization leaves out the complexities of the patient’s life. On the contrary, what-is-available-based care -as the resident puts it- works, because it takes into account the different aspects of the patient’s life, affected by, and which influences, the development of her condition.

What-is-available-based care does not make reference exclusively to providing care in a context with limited resources; I use it in reference to a kind of practice that takes into account the patients’ lives, their expectations, possibilities and preferences. Improvisation is not taken negatively as a lack of order but as a necessary condition to being flexible and to attuning with patients’ needs. Instead of trying to make the patient fit into pre-established medical categories, what-is-available-based care introduces changes in those categories to fit the patient’s story. Mol describes this process of attuning in this way: ‘identifying a suitable target value is not a condition for, but a part for, treatment. Instead of establishing it before you engage in action, you keep on searching for it while you act’ (Mol 2008). Following Mol, what-is-available-based care is an example of good care in practices as facts and values are attended jointly and care is concerned with a life affected by a disease, not just a body. Care entails flexibility and adaptability:

‘somehow technology, daily habits and people’s skills and propensities have all to be mutually adjusted. This is crucial in the logic of care. It is important to attune everything to everything else. Nothing is taken to be entirely fixed or entirely fluid’ (Mol 2008, 61).

At the van, the flexibility to continuously adapt to the patient’s precarious living conditions is taken as a sine-qua-non condition to provide care. Still, this flexibility is

---

<sup>113</sup> ‘Aquí en lugar de medicina basada en la evidencia lo que aprendemos es medicina basada en lo que hay’

possible because they do not need to comply with the organizational agendas of the primary healthcare centres.

In the what-is-available-based care approach there is no room for “cultural difference” as it is taken for granted that patients’ values cannot be detached from their biological facts. As care is not exclusively based on theoretical ideals –as is the case in evidence-based- medicine – there is not a “standard culture” among which to measure the cultural difference of the others. It is about how to address health issues embedded in the complexity of lives, not about processes of recognition based on established categories. At the van, the physician and nurse question those categories which define the settlement dwellers as “different people” (people with their own idiosyncrasy as they call it in the CPE report) who need to be re-educated. Similarly, they challenge the humanitarian framework that defines their work by grounding their practices in the recognition of the right to healthcare as a universal right. It is not the logic of compassion and repression, in which humanitarian government is based, that guide the provision of care at the van, but the logic of care.

It is in that logic of care that what-is-available-care comes to light, making possible a type of clinical practice that is political in the sense that it is in disagreement with the institutional logic that sustains it and questions the institutional mechanisms of the recognition and accommodation of difference. In their refusal to use established categories for the people of the settlement, the practices of the van’s workers in relation to ‘cultural difference’ could be described as what Cristiana Giordano (2014) calls ‘acknowledgment’. Giordano analyses the practices of an ethno-psychiatric clinic and its entanglements with other institutions to grant citizenship to migrant women victims of trafficking. Giordano argues that the term “recognition” ‘captures both the normative basis of political claims and the violence embedded in them’ (2014, 7). Therefore she proposes *acknowledgment* instead of recognition to signal that difference exceeds categories and thus, ‘the other’ cannot be assigned with a fixed identity. Giordano defines acknowledgment as ‘the political and ethical act of surrendering the desire to know through already-established categories and of accepting understanding, and thus embracing uncertainty’ (2014, 9). In their everyday practices and by challenging the humanitarian premises of their work, the healthcare van’s workers question the representations of their Gitano patients as culturally different. For them, Gitanos’ difference is not a useful category as the

heterogeneity of their Gitano patient's lives exceeds the meaning of that category. Inasmuch the healthcare van's workers challenge the stereotypes associated to Gitanos in their practices and go beyond those stereotypes, their practices become acts of acknowledgment.

## **Concluding Remarks**

Through the analysis of the processes that triggered the creation of the healthcare van, in this chapter I have investigated the 'discourses of truth' (Foucault 2003a) constructed by the experts in social exclusion, that define the settlement dwellers as individuals to be corrected. As the van's example highlights, the institutional motto of promoting interventions to re-educate Roma intertwined with the need to stop the public health threat posed by tuberculosis. If in chapter one I argued that the Spanish version of 'reasonable anti-gypsyism' focuses primarily in conviviality issues instead of the securitarian emphasis that Van Baar (2014) refers to, in the case of the healthcare van the tuberculosis' threat moves the attention to the securitarian approach. Still, this securitarian approach was limited to the event that prompted the healthcare van's creation and the van's main objectives were grounded on the principle of "normalizing" the settlement dwellers.

The practices described in this chapter show how a humanitarian technology such as the healthcare van may afford for counterintuitive practices of care. In their everyday practices, the healthcare van's workers challenge the humanitarian framework and the expert knowledge construction of the CPE members that only award recognition to the settlement dwellers through normalization. The van's workers take advantage of the interstitial character of their work to position themselves not as a normalising technology but a facilitator to access healthcare. Adapting their practice to the living conditions at the settlement they resort to planned improvisation in order to be able to be approachable to most of the settlement dwellers.



## Conclusion

‘To live is to pass from one space to another,  
while doing your very best not to bump yourself’

Georges Perec *Species of Spaces*

The main purpose of this thesis is to assess how the idiom of “cultural difference” is constructed, manifested, used and reproduced in frontline public healthcare services. Focusing on Gitano and Roma cultural difference, I aimed to shed light onto the ‘modes of social differentiation’ (Vertovec 2014) enacted during the encounters at different primary healthcare locations. In each ethnographic chapter, I traced the meanings ascribed to Gitano (and Roma) cultural difference and the sometimes subtle, other times notable variations in the ways cultural difference was referred to and mobilized in different places in the same institutional setting: public primary healthcare. Vertovec’s conceptual framework of representations-configurations-encounters is useful to ‘take into account the relations between structural, discursive and social phenomena’ (2014, 14). Through the analysis of situated encounters, I have examined the influence of different sets of representations (about Gitanos, about professional roles among others), configurations (the structural conditions determining access to healthcare, both legally and institutionally) and the kinds of implications and consequences they have in the provision of healthcare.

I consider primary healthcare facilities to be a space ‘in which a set of social, cultural, structural and asymmetrical relations intertwine’ (Fortin 2008, 175). Still, I distinguish between different social spaces in primary healthcare because despite sharing a common institutional framework these spaces nurture different kinds of relationships. There are spatial differences between the consulting room and the admission desk, as there are differences between the latter and the healthcare van. In the thesis I have

prioritized investigating these locations as differentiated spaces since looking through those situational differences sheds light onto the multiple and complex ways in which configurations and representations influence the encounters. Unpacking these ‘repertoires of practice’ (Pols 2006) in each different location reveals their commonalities and their distinctions and ultimately, the singular understandings of citizenship, legitimacy and what “good care” means.

The decision to prioritize the locations and the healthcare workers’ side has left beyond the scope of this thesis some of the aspects I envisaged investigating in the research project and that I partially covered during my fieldwork. The voices and experiences of those Roma and Gitanos (mostly women but also men) that I interviewed and accompanied to different healthcare facilities are the great absence of this thesis. They are just present through their representations in the extracts of my field diaries, but I did not use any of the interviews I conducted with Roma and Gitanos. Neither do I analyze their experiences vis-à-vis healthcare. I opted to leave them outside of the analysis, and focused on healthcare workers for two reasons: the first one is methodological and relates to my own positionality as both anthropologist and physician during fieldwork. I found it problematic to reconcile these dual roles while investigating the patient’s perspective during the encounter. Though I felt that it was difficult to give an ethnographic account of Roma and Gitano experiences in healthcare, even assuming that it would be as partial as any ethnographic “truth” (Clifford 1986), I found I was better equipped to analyze the different mechanisms put in place in clinical settings in relation to the production and reproduction of Gitano and Roma health inequalities from the positions of healthcare workers.

The second reason is also methodological and has to do with the multiplicity of lived experiences and understandings of the healthcare processes that Gitanos have. First of all, as I already explained in chapter one, despite migrant Roma and Gitanos both falling under the EU umbrella term “Roma”, it does not mean that they identify with each other or represent themselves as “the same kind of people”. While healthcare personnel used the term ‘Gitanos’<sup>114</sup> to refer to both migrant Roma and Gitanos,

---

<sup>114</sup> In the case of migrant Roma, healthcare workers add the national origin adjective to the noun Gitano.

Gitanos and Roma are far from a homogenous group of people and cannot be described in terms of sharing a reified notion of culture. There is a wide range of 'Roma cultures' (including Gitano cultures) living in different socioeconomic positions and maybe the characteristic shared by different Roma and Gitanos is that 'they are all affected by the anti-gypsyism of the surrounding societies' (Durst 2010, 28). Consequently, both because of the difficulty to account for all the differences without homogenizing the lived experiences of Roma and Gitanos, and also to avoid the 'over-explanatory power of ethnicity' and the ethnicity lens bias, I decided to investigate the different shapes that anti-gypsyism would take in different primary healthcare practices.

There is an extra reason that explains my decision to remain on the healthcare personnel side, and it is my own engagement with my research field site. This research project emerged from my own quest to comprehend the different processes of exclusion that I witnessed (and in which I participated, too) during the years I worked in the healthcare van. It is from that clinical experience that I decided to study anthropology to be able to understand the mechanisms that rendered commonsensical the processes of curtailing access to adequate healthcare to certain people. Anthropology became to me what the philosopher Marina Garcés (2005) calls a 'blank space' or a space 'where the world's meaning is interrupted'. During this research project, the meaning of "my medical world" was interrupted, allowing me to embody a critical perspective of it, which was the initial motivation of this research project. Through the different chapters of this thesis, I aimed to make it explicit that my position as a researcher was far from an impossible neutrality and to show the different entanglements and affects involved in this research.

Another important point to consider before the discussion of the main arguments of this thesis is the choice of Roma and Gitanos to study cultural difference in this context. As previously explained in the introduction, other researches in healthcare arenas in Spain have shown how healthcare workers articulate their representations of migrant patients by comparing them with Gitanos (Seoane and Portero 2006) and how certain stereotypes are shared with migrant groups (Sàez Sellarès and López Catalán 2009). The Gitano population is represented in Spanish society as the insider other, the culturally different and therefore the comparison of new "cultural others" with Gitanos is not counterintuitive. However, despite Gitanos sharing some (mostly

negative) stereotypes with other migrant populations in the Spanish social imagination, there are some peculiarities in the case of Gitanos and Roma in this context. These peculiarities are the consequence of historical processes, which convey governmental projects of control, assimilation and ultimately segregation. This historically produced ‘mode of social differentiation’ (Vertovec 2014) of Gitanos is fully applied to Roma (with a temporal hint, as shown in chapter three), but is not fully shared with other migrant or culturally differentiated groups. Therefore, whereas the practices explored in this thesis shed light on the ‘modes of social differentiation’, specifically on how Roma and Gitanos’ difference is constructed in primary healthcare.

Having clarified the absences, the limitations and the researcher’s positionality, in what follows I will highlight what I believe to be the core elements that shape this thesis’ arguments, the anthropological questions that they rise and the body of literature they contribute to.

## **1. The map and the territory**

I borrow this quote from Jean Baudrillard (who used it to make reference to Borges’ ‘Exactitude in Science’ short story) to describe how I attempt to organize the main ideas of this thesis. I am aware that mapping the different positions that healthcare personnel adopt vis-à-vis Gitano (and Roma) cultural difference does not contain all the possibilities and thus, like ethnography itself, is incomplete. The coordinates proposed to organise these positions in the territory are also partial: there are multiple regulating axes that intersect and determine different forms of organizing social difference at the healthcare centres but I will focus on the intersection of three of these axes and the delimited areas where the available ‘repertoires of practice’ (Pols 2006) are nested<sup>115</sup>.

---

<sup>115</sup> I intentionally leave aside gender differences because it has not been the main focus of analysis of this thesis. Still, I feel my analysis and representation in axes that delimit different inequality positions is, to some extent, inspired by intersectionality theory

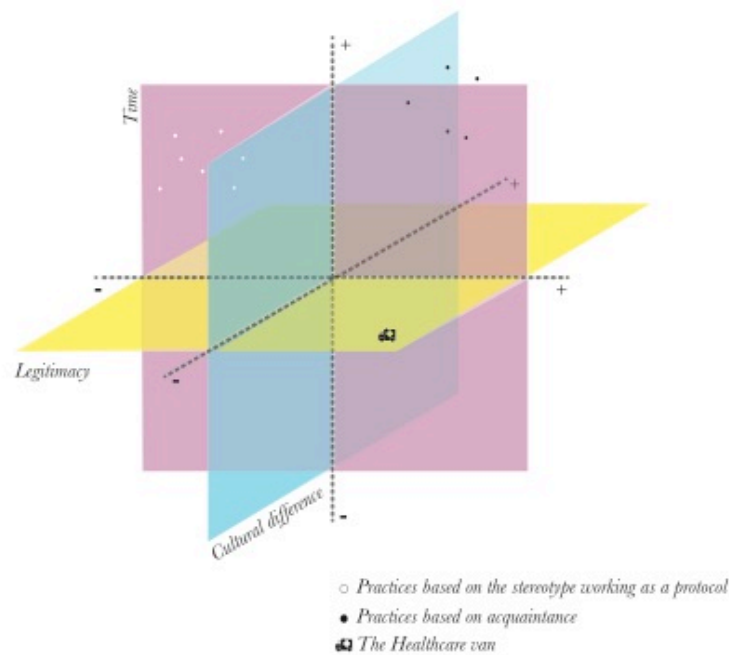


Figure 8. Time / Legitimacy / Cultural difference diagram

Bearing in mind the conceptual framework (representations- configurations- encounters) proposed by Vertovec to conduct research ‘on the modes of social differentiation and their conditioning contexts’ (2014, 14), three Cartesian axes organize the space where primary healthcare practices are enmeshed. The X plane is the legitimacy plan: it accounts for the different healthcare workers’ positions in relation to healthcare-related deservingness. The Y plane represents the identification of Gitanos and Roma as culturally different: from a radical stereotypical identification, to a hesitant one or to the invisibility of that difference. The Z plane stands for the organizational resources that I represent as time availability because it was the resource that healthcare personnel refer to as being the most precious. Therefore the Z plane spans from the ideal scenario where time is available on demand to the opposite scenario where time is a scarce resource to be distributed. These three planes and their intersections delimit eight different areas through which healthcare personnel navigate and position themselves in different encounters.

The purpose of organizing this map through the three axes is double: First, it “visualizes” the spaces of possibility demarcated by the intersection of these principles

in their enactments. Secondly, this kind of visualization as a map with its constellation of possible positionalities stresses the idea that healthcare personnel's roles are flexible and influenced by the contextual. As I have shown in chapter two, three and four, healthcare personnel inhabit different role positions depending both on their understanding of their role (representations) and the situated practices in which they enact this role. In fact, they choose to enact different facets of their role depending on the encounter. The representation as a map of practices accounts for the multiplicity of positions and the flexibility of healthcare personnel in their ability to navigate from one to another. Obviously, some of the individuals I observed in their work tended to move through role positions within similar parameters, and were coherent with their understanding of what good care was. Still, there was enough room for differentiation and accommodation depending on the contingencies of daily work and the situated knowledge.

The intersection between the legitimacy and cultural difference planes gives an idea of how the 'use of stereotypes as protocol' comes into existence. At the healthcare centre, legitimacy can be granted or denied on different bases: at the admission desk it is the law regulating access to healthcare that determines legitimacy while in the consulting room it depends on the reasons for seeking care (for example cosmetic questions are not a legitimate reason for visiting a physician or nurse). However, this ideal framework of recognition (or granting legitimacy) is enacted in multiple ways in practice. The identification of patients as Gitano, for instance, may curtail their right as citizens to access healthcare as they are portrayed as illegitimate in the social imagination. Structural constraints influence the way legitimacy is put in practice, too. As described in chapter two, at the admission desk 'stereotypes work as a protocol' when identification is solely based on negative stereotypes and the available resources are meagre, and ultimately this practice contributes to the reproduction of the inequalities in accessing healthcare that Roma and Gitanos face. In the consulting room, the social illegitimacy that teenage pregnancy represents and the one-time provision of care prompts the detachment of the biological from the biographical and the restriction of care to the concrete demand of that consultation. By doing so, physicians and nurses inadvertently reproduce the differential access Gitanos have to preventative measures. The van shows a completely different scenario: as legitimacy is neither reckoned on the legal framework basis (though they abide by it to process healthcare cards) nor the reason for seeking care and scarce resources (mainly time)

are distributed according to the assessment of the patient's needs, there are no practices that resemble the stereotypes working as a protocol. The healthcare van's practices are located on the margins of this map as the cultural difference axis is not core to their practice and legitimacy takes a different meaning. Similar to the population they attend to, the healthcare van remains in marginal positions, in the interstitial space.

Locating the primary healthcare practices in the intersections of these axis shows how the provision of healthcare to Gitanos is much more complex than the rather homogeneous discourse that healthcare workers have about Gitanos. In this way, I attempt to show how the 'reasonable anti-gypsyism' (Van Baar 2014) that organized the discourse of healthcare workers is reinforced through some practices while it seems to disappear in others. The discourse that depicts Gitanos as ill-timed patients (be it asking for appointments at the wrong time or being pregnant at the wrong age) pertains to the discourse of 'reasonable anti-gypsyism' to the extent that 'it is not "we" but "they" who violate rights and fail in their duties' (2014, 29). Practices based on stereotypes reproduce and consolidate the idea that Gitanos are ill-timed and thus, illegitimate people. Furthermore, through the analysis of the practices at the healthcare centres, it is evident how, in this context, reasonable anti-gypsyism is mainly concerned with conviviality issues. For instance, the different ways the admission desk personnel explain why Gitanos are less legitimate than any other citizen, are grounded on the alleged Gitanos' innate unruliness. As 'individuals to be corrected' (Foucault 2003a), Gitanos pose problems in the way they use public healthcare facilities, which ultimately is a conviviality problem. Similarly, Gitanos' unruliness prevents them from observing the adequate biomedical and social norms, which in public healthcare arenas transform them into non-compliant patients and populations that have ill-timed reproductive patterns.

Still, there are other practices where the process of ethnic identification takes a different route and does not reproduce Gitano and Roma inequalities in healthcare. I described those practices in chapters two and three and referred to them as identification through acquaintance, because it is through the relationship over time that healthcare workers go beyond the symbolic ethnic boundaries that situate Gitanos outside of the realm of citizenship. In those practices, ethnic identification takes place through a process in which the patient herself participates, as the

biographical account has to be disclosed by her. Identification through acquaintance, besides making it possible to attune care to the patient's needs, reflects upon the inclusion of Gitanos not only as recipients of care but also as active members during consultations. Unlike the biological, a biographical approach is not possible without the patient's participation: 'unlike the "truth" of the disordered body, visible through examinations or biochemistry, the truth of the subject cannot be exposed without the explicit permission of the subject concerned (May 1992; quoted in Lupton 1994) .

Whereas healthcare workers are the only ones involved in ethnic identification processes based on stereotypes, in those practices based on acquaintance ethnic identification is conjointly enacted between the patient and the healthcare worker. Paradoxically, these practices do not affect the discourse that healthcare workers have about Roma and Gitanos; instead, healthcare workers defend themselves from the suspicion of "positively discriminating Gitanos" that the dominant reasonable anti-gypsyism raises. Hence, positive experiences with Gitanos remain in the private domain of the consultations but do not challenge the prevailing negative stereotypes of public discourses. These practices are rendered invisible to the public and if shared, they provoke the need to justify they are not a treatment of favour to Gitanos. Similarly to the process of 'symbolic contagion of the stigma' (Sarradon-Eck, Farnarier, and Hymans 2014) described for the van's workers, those healthcare workers whose practices are based on acquaintance are suspicious of being as duplicitous as their Gitanos patients.

The "interstitial" qualities of the van position its practices in the margins of the territory of primary healthcare practices. Despite this, there are enactments of care that are similar to those described at primary healthcare centres. In the van the categories that organize care on the three axis described are displaced. The plane of cultural difference does not exist as such, because there is not a "standard culture" against which to measure cultural difference. Furthermore, as care is provided at the settlement, embedded in the organization of the precarious lives of the settlement inhabitants instead of the institutional logic, the biographical approach imposes itself in the provision of care. The biographical becomes central not only during the consultation but it is also crucial for the management of time and organization of work in the van. As described in chapter four, in the healthcare van both the organization and the distribution of resources are grounded on the knowledge that the physician and nurse have of the patients, their social and material resources and



the severity of their afflictions. Acquaintance allows for ‘inclusive triage’ and it is a sine-qua-non condition for the van’s workers to attune with their patient’s needs. This attuning of infrastructures and technologies with people’s needs is the way care is provided in the van, what I call (borrowing the resident’s words) ‘What-is-available-based medicine’. The practices at the van become a “space of mediation” where institutional categories are challenged and a shared therapeutic framework is negotiated between the patients and physician.

Interestingly, the van’s creation followed the discourse of humanitarianism described by Didier Fassin (2011b) but this discourse is subverted through the situated practices of the van’s physician and nurse. The van’s example shows that the practices produced under humanitarianism may be not as straightforward as expected. My aim in chapter four was not to denounce the contradictions of humanitarian discourses but to investigate the different ways care is enacted in the van and how, being aware of the paradoxes of their position, the van’s workers find a way to go beyond the humanitarian framework and provide care and recognize the right to healthcare of the settlement inhabitants. To do so, the a-priori categories used to define the settlement dwellers (high mobility, unsanitary citizens, excluded) are discarded in the van. Instead, the settlement dwellers’ differences are ‘acknowledged’ because ‘difference exceeds categories, the other cannot be assigned a fixed identity, only an opaque and shifting sense of belonging’ (Giordano 2014) and this acknowledgment entails changes in previously established discourses, be it the humanitarian logic of compassion and repression or the discourse regarding the van’s workers’ professional roles. Paradoxically, it is at this interstitial service that the workers feel they are less constrained by institutional rules.

The three previously described axis are a means to arrange the constellation of professional positionalities available at the primary healthcare centre: they spatially represent the repertoires of practice in relation with Gitano cultural difference. Healthcare workers navigate this territory and locate themselves in different professional positions depending on the situated encounter as the ethnographic examples show. The map illustrates how the prevailing ‘reasonable anti-gypsyism’ in the discourse is more nuanced in situated practices and its appearance is much more contextual, depending on the need to distribute scarce resources. However, the positive practices with Gitanos in clinical encounters do not modify the prevailing

discourses about Gitanos. The van's practices are located in the margin of this territory, highlighting its interstitial and "extraordinary" character: interstitial because of its position in the margin of the healthcare system (and of spaces of citizenship) and extraordinary because it is not organized by the same three axes. Having represented the flexibility and variability of the professional roles that the healthcare workers inhabit at the primary healthcare centres, in what follows I present how Gitano difference is problematized in this context and its relation with different ideas of citizenship and with competing ideas about the role of primary healthcare.

## **2. Gitano and Roma difference as a matter of time**

Time appears as a core idea through which Roma and Gitanos cultural difference is understood in primary healthcare. The translation of Gitano "unruliness" into the category of ill-timed patients is not accidental: time and the different temporal frameworks that mould clinical practice are crucial in the way healthcare workers understand their work. Through the different ethnographic chapters, the focus on time as a conceptual problem shows the different temporalities that ultimately determine 'how and when lives matter, interpersonal obligation and the organizational pressures that bear on clinical work' (Lochlann Jain y Kaufman 2011). In this context, the tensions credited to Gitano difference are mostly framed as differences in temporality. In chapter two I have shown how the adequate use of time determines the legitimacy to get an appointment. The representation of Gitanos as illegitimate populations is translated in temporal terms when their request for immediate medical appointments is perceived as mischievous, a product of Gitanos incapacity to comply with the rules. Gitanos are portrayed as ill-timed patients at the admission desk, reflecting on the situated processes through which health-related deservingness is measured and their citizen rights questioned.

Chapter three explores how different temporal frameworks shape the relationship with Gitanos in the consulting room. The ethnification of teenage pregnancy as a Gitano cultural phenomenon clashes with two temporal frameworks: first Gitanos as a social body have ill-timed reproductive patterns and secondly, this reproductive pattern – understood by healthcare workers as a consequence of their culture- does not allow them to progress like the rest of Spanish society and thus, they are

backwards and excluded from the main social body. Similarly, Gitanos are portrayed as ‘unsanitary citizens’ (Briggs and Mantini-Briggs 2003) inasmuch as they do not fully embrace the preventative measures proposed by biomedicine. At the consulting room, Gitano’s difference stands for the temporal incongruities between the clinical and patient’s frameworks. As Brodwin reminds us, time rests at the core of healthcare practice through the moral obligation to intervene on time to stop the progression of the pathological processes (Brodwin 2011). However, this temporal logic (therapy, progress, longitudinality) entails a moral economy of relationships (Fabian 2002) in which Gitanos are delegitimized as citizens as their relationship to time differs from the biomedical temporal framework.

The construction of teenage pregnancy as a socio-medical problem is not exclusive to this context (Hacking 1999; see also Arney and Bergen 1984 for a hystorical account) but the ethnic character conferred to it transforms ‘stratified reproduction’ (Ginsburg and Rapp 1995) into an ethnic issue. Teenage pregnancy becomes a problematic topic in clinical encounters, as do Gitano reproductive patterns, an aspect that Ayala Rubio (2008) already noticed in her research on health-related attitudes among Gitanos in Madrid. In the report she signals the unequal treatment that some Gitanos perceive in relation with the insistence of some healthcare workers on recommending fertility prevention techniques for Gitano populations (2008, 144). My own research shows that Gitano reproductive patterns is a topic fraught with tensions in clinical arenas and, as shown in chapter three, it challenges the normative and ‘objective’ understandings of what good practice is.

Similarly, the assumption that Gitanos do not embrace preventative measures is based on the alleged fatalism of Gitanos (Ramos-Morcillo et al. 2014; Ferrer 2003), which has already been questioned in other research that have highlighted the diverse practices in relation with preventative measures among Gitanos (cf. Ayala Rubio 2008). Still, the preference for a present temporal framework over a preventative biomedical framework is one of the representations of Gitanos among physicians and nurses. The discourse about Gitano teenage pregnancy and their apparent resistance to prevention are the clinical translation of the general representation of Gitano culture as entailing unruliness and the consequences of that unruliness in the social and physical body. Ultimately these representations show the entanglement of negative stereotypes about Roma and Gitanos in wider Spanish society with the

normative biomedical ‘regimes of living’<sup>116</sup> (Collier and Lakoff 2008) to portray them as deviant individuals. The representation of Gitanos as ‘individuals to be corrected’ is translated in public healthcare as ‘ill-timed patients’ who are incorrigible due to their culture. Nevertheless the healthcare system tries to re-educate their incorrigibility by deploying different normalization techniques, such as the healthcare van. For healthcare workers (as representatives of wider Spanish society) living in settlements, having children during adolescence, not embracing biomedical preventative discourse or biomedical treatments, are all causes and consequences of Gitano culture, erasing the social and historical conditions that led to the segregation of Gitanos in Spain. Instead of focusing on the structural conditions that prevent Gitanos from accessing quality and adequate healthcare and devising mechanisms to revert them, the healthcare institution responds to what is considered Gitanos’ difference similarly to other institutions and creates a new technical intervention to “re-educate” or control Gitanos.

Finally, the use of temporal incongruities to refer to Gitano cultural difference is connected to the specific organizational use of time in healthcare centres, too. The organizational rhythms and different categorizations and sequencing of the activities at healthcare centres are characteristics of welfare bureaucracies (Lovell 1992) and taken for granted in their work. Time and its availability epitomize the adequateness of institutional infrastructures to provide care. Healthcare workers refer to lack of time to complain about the difficulties of providing care with limited resources. As the pictures of the consultation’s doors in the prologue show, consultation time is a precious and limited resource and patients should be aware of it and need to behave consequently. The presentation of time as a limited resource are, as Auyero argues, ‘temporal processes in and through which political subordination is reproduced’ (Auyero 2012). During the uncertain times when I conducted fieldwork, the privatization processes were pending on a court decision while the meagre primary care budget was being reduced again and again. In that atmosphere of uncertainty about the future of the public healthcare system, everyday practices were fraught with

---

<sup>116</sup> Collier and Lakoff describe regime of living as ‘situated configurations of normative, technical, and political elements that are brought into alignment in problematic or uncertain situations’ (2008, 31).

these temporal contradictions: the future of the healthcare system was defended while current resources were reduced.

### 3. Gitanos and Roma difference as professional boundary

‘No work, be it clinical or anthropological can do without entry into the affective tissue of domestic spaces’

Joao Biehl Care and Disregard

Throughout the ethnographic chapters I have shown the different ways primary healthcare workers construct Gitanos’ difference in their ordinary practices and how they move from flexible and provisional positionalities depending on their situated practices. Through the ethnographic vignettes I analysed how the notion of cultural difference comes into play at the clinical encounters and I investigated its different meanings. I have already argued that Gitanos’ representations in primary healthcare built on Gitanos’ representations in wider society but there are moulded by the specific context of primary healthcare. Nevertheless, when cultural difference comes into play in the clinical encounters, not only does it signal to the clashes between Gitanos and Payos’ perspectives, it also highlights the different understandings of the professional role hold by healthcare workers. These differences are basically related to the ways in which healthcare workers rationalised their actions with respect to what they consider a good practice. In table one, I display a set of opposing pairs that reflect on the different understandings of professional roles.

Protocol	Objective/standardized	Biological
Acquaintance	Subjective/ multiplicity	Biographical

The opening quote from Joao Biehl makes reference to the affective and intimate character of clinical (and anthropological) practice; a reference that seems quite at distance from the sterile, neutral and scientific character used to describe healthcare facilities. The primary healthcare centres are far from being aseptic and neutral

places, instead they are relational spaces where different actors deposit their experiences and aspirations, being those aspirations as different as for instance to contribute to social justice, to get paid at the end of the month or to find the adequate treatment for a back pain. Annemarie Mol (2008) contrasts the logic of care with the logic of choice to highlight the underlining principles of both logics and the differences between them. Both logics coexist in a tense and flexible interrelationship at the healthcare centres and one of these logics is prioritised over the other in different encounters and in relation to cultural difference, too. For instance, in the obstetric vignette, the managerial logic imposed itself to deal with the body-object in a standardized manner as a response to the unapproachable biographical account of the patient. The separation of facts (the pregnant body) from values (teenage pregnancy) allows the obstetrician to provide what may be considered good care in managerial logic: the obstetrician followed the prenatal care guideline and that is a synonym of good practice. The cultural explanation the obstetrician gave to teenage pregnancy delimits what rests outside of the clinical realm: the mundane and messy life of the patient-body. This example clearly illustrates how, in this context, cultural difference is used to delimit the realm of biomedical practice to the physical accompanied by an ideal of good practice which is judged in terms of standardized procedures (such as guidelines, protocols and so on).

Similarly, at the admission desk Gitano difference was used to explain the mismatch between the patient's needs and the protocol's guidance. In these cases, administrative staff, likewise the obstetrician, act with respect to an idea of the good that is based on the strict compliance with the established protocols. The standardized and "objective" approach to patients, once brought to biomedical practice to determine its jurisdiction over the body (Timmermans and Berg 2003), still functions as a means to delimit the body and just the body as the realm of biomedicine. In the case of the administrative staff, the fact of complying with protocols renders their practice evaluable and justifiable, while reducing these practices to the administrative tasks. Moreover, the standardized approach may privilege the institutional needs for data over the particular needs of individual patients (Swinglehurst, Greenhalgh, and Roberts 2012). Standardization and evaluation go together in the organizational logics that seek for measurable practices in order to evaluate performances. As Lamont et al. (2014) contend, standardization and evaluation are cultural processes that pertain to the broader category of rationalization, which ultimately contribute to the reproduction

(and production) of inequality. About standardization these authors admit that while standards implementation is usually motivated by positive purposes, ‘once institutionalized, standards are often mobilized in the distribution of resources’ (M. Lamont, Beljean, and Clair 2014, 20). In my research context, standardization was praised as a means to provide quality and equal healthcare but, similarly to any other technology, its unintended effects is that, *de facto*, serves to diminish access to healthcare. Cultural difference comes to light when the patient does not fit in the standard categories, delimiting the biomedical realm to the body and the administrative realm to the papers and not the people.

At the healthcare centres, practices are systematized through the organizational techniques of standardization and evaluation. Still, as I have shown in chapter two and three, there are some practices where standardization is downplayed and the patient’s needs are put to the front. In those practices cultural difference is enmeshed in the biographical account as another characteristic of the patient’s life, which is also at the core of the clinical encounter. In those encounters where the biological facts are not separated from the biographical, the realm of biomedicine expands from the physical body and what is considered a good practice is to attune with the patient’s needs. Those practices are, as Biehl reminds us, enmeshed in ‘the affective tissue of domestic space’ (2012, 262). The patient’s biographies are put at the centre of the encounters, they are not cast aside as a disturbance to provide adequate care, like is the case in the practices based on standardized care. The examples of practices based on acquaintance at the admission desk, nicely show how the administrative clerk understands her work as part of the process of caring for the patients, and not only filling up forms and giving appointments. Or even in the act of filling up forms, the way explanations are given are enactments of care. Yet, some biographical aspects may directly clash with the normative biomedical knowledge, such as the desire to be pregnant at a young age. Those socially deviant biographies tend to become an ‘event’ (Povinelli 2011) as they become an ethical issue that should be reflected upon. In those cases, either the principles of biomedicine and its “neutrality” are questioned or these principles are reinforced by designing programs and interventions to “correct” the social deviance.

Finally, the practices at the healthcare can escape the standardization and evaluation processes that organise the practices at the healthcare centres and profiting from its

interstitial character, the van's workers redefine their professional roles to adequate it to the needs of the settlement dwellers. In their case, the way they understand the settlement dwellers differences<sup>117</sup> introduce changes in the established discourses (basically those of eradication and perpetuation) about the settlement and about their professional roles. Interestingly, a technology (the healthcare van) devised under a humanitarian framework allows for practices based in the logic of care. Similarly, the van's workers challenge the 'inclusive exclusion' (Picker 2012) by discarding the re-education objective and grounding their work on the right to access healthcare. On the one hand, these counterintuitive effects of the healthcare van's work are possible because the healthcare workers understand their practices as broader than the physical sphere. On the other hand, the 'longitudinality' of care - secured by long term contracts and institutional recognition - is fundamental to be able to attune with the settlement dwellers' needs. Lorenzo Alunni conducted research on a similar healthcare van working in Roma camps in Rome and he contends that the van's practices contribute to exclude Roma from healthcare facilities (Alunni 2015), which seems the expected result bearing in mind the humanitarian underpinning of both healthcare vans. My argument is that despite the humanitarian framework that governs the precarious lives at the settlement, there are sites of resistance within that framework. The healthcare van shows the incongruence between the institutional configurations and the situated practices. However, the healthcare van's practices do not manage to modify neither the institutional discourse nor its organization and, similarly to the case of the acquaintance practices at the healthcare centre, the prevailing reasonable anti-gypsyism remains unchallenged.

## **Concluding remarks**

In this dissertation I draw on the anthropological research that explore the relationship of biomedicine and culture and the literature about care in order to provide an ethnographic account of how cultural difference is enacted in healthcare contexts. In this way, by analysing how "Gitano difference" is constructed as a

---

<sup>117</sup> Including in the heterogeneity of the settlement Gitanos' difference among others.



category of practice in the primary healthcare centres where I conducted fieldwork, this dissertation provides an example of how healthcare workers draw on essentialised ideas about Gitano culture to make sense of the clinical encounters with those who are identified as Gitanos. However, Gitano difference is not only built upon a reified notion of Gitano culture: the specific temporal frameworks and conceptualizations of the body through which healthcare workers understand their clinical practice contribute to the construction of this category, too. The ethnographic material shows how, in the case of Gitanos patients, cultural difference comes to represent those aspects that distinguish Gitanos from the “average patient”, a patient that coincides with Rose and Novas concept of ‘biological citizenship’ (2008). In this way, cultural difference does not only represent a deviation from the norm in the consulting room but also a deviation from the norm that constructs Gitanos as illegitimate citizens, which ultimately curtail their access to healthcare and perpetuates their exclusion. This thesis contributes to the literature on health-related deservingness (Sargent 2012) showing how Gitanos’ representations as illegitimate patients depend both of the negative representations of Gitanos in the wider social imaginary and the local configurations and situated contexts where clinical encounters take place.

The thesis contributes to the literature on humanitarianism in two different ways; first, by providing an example of how humanitarian logics underpins the criteria to gain access to healthcare, creating what I called the hierarchy of legitimacy. Secondly, the analysis of the healthcare van, which was designed as a humanitarian service, shows how the van healthcare workers circumvented the humanitarian logics in their clinical practices. Therefore, the van’s example documents the space of possibility of ‘interstitial services’ to sidestep humanitarianism and reorient the van as a service that understand access to healthcare as a basic human right instead of access based on compassion. The van’s ethnographic material shows how a service conceived under a humanitarian logic, paradoxically becomes an example of practices grounded in the logic of care.

Throughout the thesis the analysis of ethnographic material has shown different enactments of care in primary healthcare in Madrid and how they are related to the construction of Gitano difference as a category of practice. In that way the thesis contributes to the literature on care showing the multiple ways that Gitano difference is enacted at the different locations in primary healthcare and how these enactments

are related to different ways of understanding good care. Focusing on the situated encounters in a public institution such as healthcare, this dissertation participates in wider debates about the institutional responses to diversity.

Throughout the dissertation I have shown how cultural difference frequently signals tensions in the clinical encounters with Gitanos. Further research would shed light on the shared (or not) mechanism put in practice with other “cultural others”. Providing a detailed account of the processes that produce and reproduce Gitanos and Roma representations as illegitimate populations -which ultimately justify their exclusion from full right citizenship- this dissertation aims to contribute to the broader debate about Roma in Europe. Similarly the dissertation shed light into the cultural processes through which Gitano’s unequal access to healthcare is reproduced in everyday practices. Incorporating the analysis of Gitanos and Roma experiences when using public healthcare could be a fruitful future research avenue and provide crucial understanding of the processes I investigate in this dissertation.

## References

- Adler, P. A., and P. Adler. 2000. 'L'autocensure dans le sujets sensibles'. In *L'Éthique dans la Pratique des Sciences Humaine: Dilemmes*, edited by Jacqueline Feldman, 163–80. Paris: Editions L'Harmattan.
- Aguilera, Thomas. 2016. 'Normalizing and Regularizing Slums : What Explains the Sidelineing of Onsite Interventions in Europe ? Comparing Paris and Madrid'. In *Rethinking Precarious Neighborhoods*, edited by Agnès Deboulet, 161–76. Paris: AFC. <http://librairie.afd.fr/etudes-13-precarious-neighborhoods/>.
- Ahmed, Sara. 2004. *The Cultural Politics of Emotion*. Edinburgh: Edinburgh University Press.
- Alpert, Joel J., and Evan. Charney. 1973. *The Education of Physicians for Primary Care*. DHEW Publication ; No. (HRA) 74-3113. Rockville, Md.: U.S. Dept. of Health, Education, and Welfare, Public Health Service, Health Resources Administration, Bureau of Health Services Research. <https://catalog.hathitrust.org/Record/001557980>.
- Alpuente, Mocho. 1999. 'Pistas de Malmea'. *EL PAÍS*, July 10. [http://elpais.com/diario/1999/07/10/madrid/931605860\\_850215.html](http://elpais.com/diario/1999/07/10/madrid/931605860_850215.html).
- Alunni, Lorenzo. 2015. 'Securitarian Healing: Roma Mobility and Health Care in Rome'. *Medical Anthropology* 34 (2): 139–49. doi:10.1080/01459740.2014.962693.
- Appadurai, Arjun. 2013. *The Future as Cultural Fact: Essays on the Global Condition*. London: Verso.
- Aragón Martín, Beatriz. 2017. 'Women's Rights or "Unborn" Rights? Laws and Loopholes in Madrid's Public Healthcare Services' Abortion Provision to Migrant Women'. In *A Fragmented Landscape: Abortion Governance and Protest Logics in Europe*, edited by Silvia De Zordo, Joanna Mishtal, and Lorena Anton, 169–86. Protest, Culture and Society, volume 20. New York: Berghahn Books.
- Arney, William Ray, and Bernard J. Bergen. 1984. *Medicine and the Management of Living: Taming the Last Great Beast*. Chicago: University of Chicago Press.
- Auyero, Javier. 2012. *Patients of the State: The Politics of Waiting in Argentina*. Durham: Duke University Press.
- Ayala Rubio, Ariadna. 2008. 'Actitudes y Pautas de Comportamiento de La Población Gitana de La Comunidad de Madrid En Relación a Su Salud'. Madrid: Instituto Salud Pública Comunidad de Madrid.
- . 2012. 'Las Políticas Sociales En Perspectiva Socio-Antropológica: Estudio de La Gestión y Aplicación de La Renta Mínima de Inserción de La Comunidad

- de Madrid Con El Colectivo Gitano'.  
<http://eprints.ucm.es/16247/1/T33960.pdf>.
- Barnes, David S. 1995. *The Making of a Social Disease: Tuberculosis in Nineteenth-Century France*. Berkeley: University of California Press.
- Beluschi Fabeni, Giuseppe, Juan F. Gamella, and Elisabeth Gómez Oehler. 2015. 'Extended Survey Report. University of Granada. MigRom Project. The Immigration of Romanian Roma to Western Europe: Causes, Effects, and Future Engagement Strategies'.  
<https://doi.org/10.13140/RG.2.1.2096.2404>.
- Beluschi Fabeni, Giuseppe, Juan de Dios López López, and Stefano Piemontese. 2014. 'Between Assimilation and Heritagization. The Linguistic Construction of Gitanos in Spanish Housing Policies'. In *Wor(l)Ds Which Exclude, The Housing Issue of Roma, Gypsies and Travellers in the Language of the Acts and the Administrative Documents in Europe*, edited by Leonardo Piasere, Nicola Solimano, and Sabrina Tosi Cambini, 81–116. Fiesole: Fondazione Michelucci Press.  
[http://www.michelucci.it/wp-content/uploads/2015/fm2007/ebook\\_WE\\_final\\_0.pdf](http://www.michelucci.it/wp-content/uploads/2015/fm2007/ebook_WE_final_0.pdf).
- Benedicto Subirà, Clara. 2013. 'De Mayor quiero ser Escritor Titular'. *Medicos de Familia* 15 (4): 34.
- Benmarhnia, Tarik, Maria-Victoria Zunzunegui, Alicia Llácer, and Francois Béland. 2014. 'Impact of the Economic Crisis on the Health of Older Persons in Spain: Research Clues Based on an Analysis of Mortality. SESPAS Report 2014'. *Gaceta Sanitaria* 28, Supplement 1 (June): 137–41.  
doi:10.1016/j.gaceta.2014.02.016.
- Bereményi, Bálint-Ábel. 2012. 'Cuando la etnicidad supedita la nacionalidad. Complicando la noción de minoría modelo entre inmigrantes "del este" en España.' In *Actas del I Congreso Internacional sobre Migraciones en Andalucía*, edited by F. Javier García Castaño and Nina Kressova. Granada: Instituto de Migraciones.
- Bereményi, Bálint-Ábel, and Anna Mirga-Kruszelnicka. 2012. 'Lost in Action? Evaluating the 6 Years of the Comprehensive Plan for the Gitano Population in Catalonia.' Barcelona.  
[https://www.academia.edu/2372922/Lost\\_in\\_Action\\_Evaluating\\_the\\_6\\_years\\_of\\_the\\_Comprehensive\\_Plan\\_for\\_the\\_Gitano\\_Population\\_in\\_Catalonia](https://www.academia.edu/2372922/Lost_in_Action_Evaluating_the_6_years_of_the_Comprehensive_Plan_for_the_Gitano_Population_in_Catalonia).
- Berg, Marc. 1997. 'Problems and Promises of the Protocol'. *Social Science & Medicine* 44 (8): 1081–88. doi:10.1016/S0277-9536(96)00235-3.
- Berg, Marc, and Annemarie Mol, eds. 1998. *Differences in Medicine: Unraveling Practices, Techniques, and Bodies*. Body, Commodity, Text Y. Durham, NC: Duke University Press. <http://dx.doi.org/10.1215/9780822399179>.
- Berra, S, and JM Elorza-Ricart. 2009. 'Salud y Uso de Los Servicios Sanitarios En Población Inmigrante y Autóctona de España.' AATRM 2007/08. Madrid: Ministerio de Ciencia e Innovación. Agència d'avaluació de Tecnologia i Recerca Mèdiques de Catalunya.
- Biehl, João. 2012. 'Care and Disregard'. In *A Companion to Moral Anthropology*, edited by Didier Fassin, 242–63. Chichester, UK: John Wiley & Sons, Ltd.  
doi:10.1002/9781118290620.ch14.

- BOCM. 2009. 'Ley 6/2009, de 16 de Noviembre, de Libertad de Elección En La Sanidad de La Comunidad de Madrid.'  
<https://www.boe.es/buscar/pdf/2009/BOE-A-2009-9047-consolidado.pdf>.
- BOE. 1990. 'Instrumento de Ratificación de La Convención Sobre Los Derechos Del Niño, Adoptada Por La Asamblea General de Las Naciones Unidas El 20 de Noviembre de 1989'.
- . 2000. 'Ley Orgánica 4/2000, de 11 de Enero, Sobre Derechos y Libertades de Los Extranjeros En España y Su Integración Social'.  
<https://boe.es/buscar/act.php?id=BOE-A-2000-544>.
- . 2001. 'Resolución de 5 de Julio de 2001, de La Secretaría General Técnica, Por La Que Se Da Publicidad Al Convenio de Colaboración Entre El Ministerio de Trabajo y Asuntos Sociales, a Través Del Instituto de Migraciones y Servicios Sociales (IMSERSO), La Comunidad de Madrid y El Ayuntamiento de Madrid, Para El Desarrollo de Actuaciones Conjuntas En Materia de Atención a Inmigrantes Nómadas'.  
<https://www.boe.es/boe/dias/2001/07/27/pdfs/A27635-27637.pdf>.
- . 2012. 'Real Decreto-Ley 16/2012, de 20 de Abril, de Medidas Urgentes Para Garantizar La Sostenibilidad Del Sistema Nacional de Salur y Mejorar La Calidad Y Seguridad de Sus Prestaciones'.  
[https://www.boe.es/diario\\_boe/txt.php?id=BOE-A-2012-5403](https://www.boe.es/diario_boe/txt.php?id=BOE-A-2012-5403).
- Borrell-Carrió, Francesc, Anthony L. Suchman, and Ronald M. Epstein. 2004. 'The Biopsychosocial Model 25 Years Later: Principles, Practice, and Scientific Inquiry'. *The Annals of Family Medicine* 2 (6): 576–82. doi:10.1370/afm.245.
- Bridges, Khiara M. 2011. *Reproducing Race: An Ethnography of Pregnancy as a Site of Racialization*. Berkeley; London: University of California Press.
- Briggs, Charles L. 2005. 'Communicability, Racial Discourse, and Disease'. *Annual Review of Anthropology* 34 (1): 269–91.  
doi:10.1146/annurev.anthro.34.081804.120618.
- Briggs, Charles L., and Clara Mantini-Briggs. 2003. *Stories in the Time of Cholera: Racial Profiling during a Medical Nightmare*. ACLS Humanities E-Book (Series) Y. Berkeley, Calif., Berkeley, Calif.; London: University of California Press.  
<http://hdl.handle.net/2027/heb.31628>.
- Brodwin, Paul. 2011. 'Futility in the Practice of Community Psychiatry'. *Medical Anthropology Quarterly* 25 (2): 189–208. doi:10.1111/j.1548-1387.2011.01149.x.
- . 2017. *Everyday Ethics*. University Of California Press. Accessed January 17.  
<https://www.dawsonera.com/abstract/9780520954526>.
- Brooks, Fiona. 1998. 'Women in General Practice: Responding to the Sexual Division of Labour?' *Social Science & Medicine* 47 (2): 181–193.
- Brubaker, Rogers. 1992. *Citizenship and Nationhood in France and Germany*. ACLS Humanities E-Book (Series) Y. Cambridge, Mass., Cambridge, Mass., Cambridge, Mass.; London: Harvard University Press, Harvard UP.  
<http://hdl.handle.net/2027/heb.01814>.
- . 2004. *Ethnicity without Groups*. Cambridge, Mass.: Harvard University Press.
- Buch, Elana D. 2015. 'Anthropology of Aging and Care'. *Annual Review of Anthropology* 44 (1): 277–93. doi:10.1146/annurev-anthro-102214-014254.

- Burger, Thomas. 1976. *Max Weber's Theory of Concept Formation: History, Laws, and Ideal Types*. Durham, N.C: Duke University Press.
- Calavita, Kitty. 2005. *Immigrants at the Margins: Law, Race, and Exclusion in Southern Europe*. Cambridge: Cambridge University Press.  
doi:10.1017/CBO9780511493942.
- Calderón-Larrañaga, Amaia, Luis A. Gimeno-Feliu, Rosa Macipe-Costa, Beatriz Poblador-Plou, Daniel Bordonaba-Bosque, and Alexandra Prados-Torres. 2011. 'Primary Care Utilisation Patterns among an Urban Immigrant Population in the Spanish National Health System'. *BMC Public Health* 11 (1): 432.
- Callon, Michel, and Vololona Rabeharisoa. 2004. 'Gino's Lesson on Humanity: Genetics, Mutual Entanglements and the Sociologist's Role'. *Economy and Society* 33 (1): 1–27. doi:10.1080/0308514042000176711.
- Calvo Buezas, Tomás. 1990. *¿España racista?: voces payas sobre los gitanos*. Barcelona: Anthropos. <https://dialnet.unirioja.es/servlet/libro?codigo=161802>.
- Canguilhem, Georges. 1989. *The Normal and the Pathological*. Translated by Carolyn R. Fawcett. New York: Zone Books.
- Carrasco-Garrido, P., A. Lopez de Andres, V. Hernandez Barrera, I. Jimenez-Trujillo, and R. Jimenez-Garcia. 2011. 'Health Status of Roma Women in Spain'. *The European Journal of Public Health* 21 (6): 793–98.  
doi:10.1093/eurpub/ckq153.
- Castañeda, Heide. 2009. 'Illegality as Risk Factor: A Survey of Unauthorized Migrant Patients in a Berlin Clinic'. *Social Science & Medicine* 68 (8): 1552–60.  
doi:10.1016/j.socscimed.2009.01.024.
- . 2012. "'Over-Foreignization" or "Unused Potential"? A Critical Review of Migrant Health in Germany and Responses toward Unauthorized Migration'. *Social Science & Medicine* 74 (6): 830–38. doi:10.1016/j.socscimed.2011.05.024.
- Castells, Manuel. 1983. *The City and the Grassroots: A Cross-Cultural Theory of Urban Social Movements*. London: Edward Arnold.
- Chavez, Leo. 1986. 'Mexican Immigration and Health Care: A Political Economy Perspective'. *Human Organization* 45 (4): 344–352.
- CIS. 2013. 'Percepción de La Discriminación En España'. Centro de Investigaciones Sociológicas.
- Clarke, Adele E., Laura Mamo, Jennifer R. Fishman, Janet K. Shim, and Jennifer Ruth Fosket. 2003. 'Biomedicalization: Technoscientific Transformations of Health, Illness, and U.S. Biomedicine'. *American Sociological Review* 68 (2): 161.  
doi:10.2307/1519765.
- Clifford, James, and George E. Marcus, eds. 1986. *Writing Culture: The Poetics and Politics of Ethnography*. School of American Research Advanced Seminar Series Y. Berkeley, Calif. ; London, Berkeley ; London: University of California Press.
- Colen, Shellee. 1995. "'Like a Mother to Them": Stratified Reproduction and West Indian Childcare Workers and Employers in New York'. In *Conceiving the New World Order: The Global Politics of Reproduction*, edited by Faye Ginsburg and Rayna Rapp, 78–102. Berkeley: University of California Press.

- Collier, Stephen J., and Andrew Lakoff. 2008. 'On Regimes of Living'. In *Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems*, edited by Aihwa Ong and Stephen J. Collier, 22–39. Oxford, UK: Blackwell Publishing Ltd.
- Cooper, Frederick. 2014. *Citizenship between Empire and Nation: Remaking France and French Africa, 1945-1960*. Princeton: Princeton University Press.
- Cortès-Franch, Imma, and Beatriz González López-Valcárcel. 2014. 'Crisis Económico-Financiera y Salud En España. Evidencia y Perspectivas. Informe SESPAS 2014'. *Gaceta Sanitaria* 28, Supplement 1 (June): 1–6. doi:10.1016/j.gaceta.2014.03.011.
- Dean, Mitchell. 1998. 'Risk, Calculable and Incalculable'. *Soziale Welt*, 25–42.
- Delgado Sánchez, Ana, Ana Távora Rivero, and Teresa Ortiz Gómez. 2003. 'Las médicas, sus prácticas y el dilema con la feminidad'. *Estudios de sociolingüística: Linguas, sociedades e culturas* 4 (2): 589–612.
- Dirección General de Atención Primaria. 2014. 'Mapa de Vulnerabilidad y Salud En La Zona Básica Del Ensanche de Vallecas'. Madrid: Servicio Madrileño de Salud.
- Douglas, Mary. 1987. *How Institutions Think*. London: Routledge & Kegan Paul.
- Dubos, René Jules, and Jean Dubos. 1952. *The White Plague: Tuberculosis, Man, and Society*. Rutgers University Press.
- Durst, Judit. 2010. "'What Makes Us Gypsies, Who Knows...?!': Ethnicity and Reproduction'. In *Multi-Disciplinary Approaches to Romany Studies / Edited by Michael Stewart and Márton Rövid.*, edited by Michael Stewart and Márton Rövid, 13–34. Budapest: Central European University Press.
- Epstein, Ronald M., and Francesc Borrell i Carrió. 2001. 'Pudor, Honor, and Autoridad: The Evolving Patient–physician Relationship in Spain'. *Patient Education and Counseling* 45 (1): 51–57.
- Fabian, Johannes. 2002. *Time and the Other: How Anthropology Makes Its Object*. New York: Columbia University Press.
- Farmer, Paul. 1997. 'Social Scientists and the New Tuberculosis'. *Social Science & Medicine* 44 (3): 347–58. doi:10.1016/S0277-9536(96)00143-8.
- . 1999. *Infections and Inequalities: The Modern Plagues*. Berkeley: University of California Press.
- Fassin, Didier. 1992. *Pouvoir et maladie en Afrique: Anthropologie sociale dans la banlieue de Dakar*. Presses Universitaires de France - PUF.
- . 2001. 'Culturalism as Ideology'. In *Cultural Perspectives on Reproductive Health*, edited by Carla Makhoul Obermeyer, 300–318. International Studies in Demography. Oxford: Oxford University Press.
- . 2005a. 'Compassion and Repression: The Moral Economy of Immigration Policies in France'. *Cultural Anthropology* 20 (3): 362–87. doi:10.1525/can.2005.20.3.362.
- . 2005b. 'An Anthropological Hybrid: The Pragmatic Arrangement of Universalism and Culturalism in French Mental Health'. *Transcultural Psychiatry* 42 (3): 347–66. doi:10.1177/1363461505055620.

- . 2009. 'Another Politics of Life Is Possible'. *Theory, Culture & Society* 26 (5): 44–60. doi:10.1177/0263276409106349.
- . 2011a. 'Racialization: How To Do Races With Bodies'. In *A Companion to the Anthropology of the Body and Embodiment*, edited by Frances E. Marcia-Lees, 419–34. Blackwell Publishing Ltd.  
<http://www.sss.ias.edu/files/pdfs/Fassin/Racialization.pdf>.
- . 2011b. 'The Mystery Child and the Politics of Reproduction: Between National Imaginaries and Transnational Confrontations'. In *Reproduction, Globalization, and the State: New Theoretical and Ethnographic Perspectives*, edited by C. H. Browner and Carolyn Fishel Sargent, 239–48. Durham, NC: Duke University Press.
- . 2011c. *Humanitarian Reason: A Moral History of the Present*. University of California Press.
- Fassin, Didier, Alain Morice, and Catherine Quiminal. 1997. *Les Lois de l'inhospitalité*. Paris: La Découverte.
- Fassin, Didier, and Mariella Pandolfi, eds. 2010. *Contemporary States of Emergency: The Politics of Military and Humanitarian Interventions*. New York: Zone Books.
- Faubion, James D. 2003. 'Towards an Anthropology of Ethics: Foucault and the Pedagogies of Autopoiesis'. In *The Ethical*, edited by Edith Wyschogrod and Gerald McKenny. Malden and Oxford: Blackwell.
- Fernández Garcés, Helios, Nicolás Jiménez González, and Issac Motos Pérez. 2015. 'Guía de Recursos Contra El Antigitanismo'. Alicante: Federación Autonómica de Asociaciones Gitanas de la Comunidad Valenciana.  
[gitanizate.com/panel/data/adjuntos/27042015204308.pdf](http://gitanizate.com/panel/data/adjuntos/27042015204308.pdf).
- Ferrer, F. 2003. 'El Estado de Salud Del Pueblo Gitano En España: Una Revisión de La Bibliografía'. *Gaceta Sanitaria* 17: 02–08.
- FOESSA. 2008. 'VI Informe Sobre Exclusión y Desarrollo Social En España 2008'. Madrid: Fundación FOESSA.
- . 2014. 'VII Informe Sobre Exclusión y Desarrollo Social En España 2014'. Madrid: Fundación FOESSA.
- Fortin, Sylvie. 2008. 'The Paediatric Clinic as Negotiated Social Space'. *Anthropology & Medicine* 15 (3): 175–87. doi:10.1080/13648470802355491.
- Foucault, Michel. 1979. *Discipline and Punish: The Birth of the Prison*. Translated by Alan Sheridan. New York: Vintage Books.
- . 2003a. *Abnormal: Lectures at the Collège de France 1974-1975*. Edited by Valerio Marchetti and Antonella Salomoni. Translated by Graham Burchell. London: Verso.
- . 2003b. *The Birth of the Clinic*. 3 edition. London u.a.: Routledge.
- . 2009. *Nacimiento de la biopolítica*. Madrid: Ediciones AKAL.
- Fox, J. E., and D. Jones. 2013. 'Migration, Everyday Life and the Ethnicity Bias'. *Ethnicities* 13 (4): 385–400. doi:10.1177/1468796813483727.
- FSG. 2009. 'Health and the Roma Community, Analysis of the Situation in Europe'. Fundación Secretariado Gitano.



[https://www.gitanos.org/centro\\_documentacion/publicaciones/fichas/48286.html.es](https://www.gitanos.org/centro_documentacion/publicaciones/fichas/48286.html.es).

- Gamella, Juan F. 2007. 'La Inmigración Ignorada: Romá/Gitanos de Europa Oriental En España, 1991-2006'. *Gazeta de Antropología* 23. <http://hdl.handle.net/10481/6990>.
- Garcés, Marina. 2005. 'La Vida Como Concepto Político: Una Lectura de Foucault y Deleuze'. *Athenea Digital. Revista de Pensamiento e Investigación Social* 1 (7): 87–104.
- García de Cortazar, A. R., A. Cabrera Leon, M. Hernan Garcia, and J. M. Jimenez Nunez. 2009. 'Attitudes of Adolescent Spanish Roma Toward Noninjection Drug Use and Risky Sexual Behavior'. *Qualitative Health Research* 19 (5): 605–20. doi:10.1177/1049732309333813.
- García, VR Cabedo, E. Ortells i Ros, L. Baquero Toledo, N. Bosch Girona, A. Montero Royo, A. Nácher Fernández, B. Sánchez-Peral Sánchez, and MA Tamborero Sanjuán. 2000. 'Cómo Son y de Qué Padecen Los Gitanos'. *Atención Primaria* 26 (1): 21–25.
- Gay y Blasco, Paloma. 1999. *Gypsies in Madrid: Sex, Gender and the Performance of Identity*. Oxford: Berg.
- . 2003. 'This Is Not a Place for Civilised People'. In *Isolation: Places and Practices of Exclusion*, edited by Alison Bashford and Carolyn Strange, 209–21. New York: Routledge. <http://trove.nla.gov.au/version/19931969>.
- . 2016. "'It's the Best Place for Them": Normalising Roma Segregation in Madrid'. *Social Anthropology* 24 (4): 446–61. doi:10.1111/1469-8676.12333.
- Geest, Sjaak van der, and Kaja Finkler. 2004. 'Hospital Ethnography: Introduction'. *Social Science & Medicine* 59 (10): 1995–2001. doi:10.1016/j.socscimed.2004.03.004.
- Gibbon, Sahra. 2007. *Breast Cancer Genes and the Gendering of Knowledge: Science and Citizenship in the Cultural Context of the 'New' Genetics*. Basingstoke: Palgrave.
- Gibbon, Sahra, and Carlos Novas, eds. 2008. *Biosocialities, Genetics and the Social Sciences: Making Biologies and Identities*. Abingdon: Routledge.
- Gili, M., M. Roca, D. Stuckler, S. Basu, and M. McKee. 2013. '2255 – The Mental Health Risks Economic Crisis in Spain: Evidence from Primary Care Centres, 2006 and 2010'. *European Psychiatry*, Abstracts of the 21th European Congress of Psychiatry, 28 (January): 1. doi:10.1016/S0924-9338(13)77118-9.
- Ginsburg, Faye, and Rayna Rapp. 1991. 'The Politics of Reproduction'. *Annual Review of Anthropology* 20 (1): 311–343.
- . , eds. 1995. *Conceiving the New World Order: The Global Politics of Reproduction*. Berkeley: University of California Press.
- Giordano, Cristiana. 2014. *Migrants in Translation: Caring and the Logics of Difference in Contemporary Italy / Cristiana Giordano*. Berkeley: University of California Press. <http://ebookcentral.proquest.com/lib/ucl/detail.action?docID=1685918>.
- Goffman, Erving. 1974. *Stigma: Notes on the Management of Spoiled Identity*. New York: JAronson.

- Good, Mary-Jo Delvecchio. 1995. 'Cultural Studies of Biomedicine: An Agenda for Research'. *Social Science & Medicine* 41 (4): 461–73. doi:10.1016/0277-9536(95)00008-U.
- Greco, Monica. 1993. 'Psychosomatic Subjects and the "Duty to Be Well". Personal Agency Within'. *Economy and Society* 22 (3): 357–72. doi:10.1080/03085149300000024.
- Gregg, Jessica, and Somnath Saha. 2006. 'Losing Culture on the Way to Competence: The Use and Misuse of Culture in Medical Education'. *Academic Medicine* 81 (6): 542–47. doi:10.1097/01.ACM.0000225218.15207.30.
- Grillo, Ralph. 2007. 'An Excess of Alterity? Debating Difference in a Multicultural Society'. *Ethnic and Racial Studies* 30 (6): 979–98. doi:10.1080/01419870701599424.
- Gupta, Akhil. 1995. 'Blurred Boundaries: The Discourse of Corruption, the Culture of Politics, and the Imagined State'. *American Ethnologist* 22 (2): 375–402. doi:10.1525/ae.1995.22.2.02a00090.
- . 2005. 'Narratives of Corruption: Anthropological and Fictional Accounts of the Indian State'. *Ethnography* 6 (1): 5–34.
- Hacking, Ian. 1990. *The Taming of Chance*. Ideas in Context ; 17. Cambridge: Cambridge University Press.
- . 1999. 'Teenage Pregnancy: Social Construction?' In *Teen Pregnancy and Parenting: Social and Ethical Issues*, edited by David Checkland and James Wong. Toronto ; Buffalo: University of Toronto Press.
- Hahn, Robert A., and Atwood D. Gaines, eds. 1985. *Physicians of Western Medicine: Anthropological Approaches to Theory and Practice*. Culture, Illness, and Healing ; v. 6. Dordrecht ; Lancaster: DReidel.
- Hajioff, Steve, and Martin McKee. 2000. 'The Health of the Roma People: A Review of the Published Literature'. *Journal of Epidemiology and Community Health* (1979-), 54 (11): 864–69.
- Harper, Ian. 2007. 'Translating Ethics: Researching Public Health and Medical Practices in Nepal'. *Social Science & Medicine*, Informed Consent in a Changing Environment, 65 (11): 2235–47. doi:10.1016/j.socscimed.2007.08.007.
- Heath, Deborah, Rayna Rapp, and Karen-Sue Taussig. 2008. '10 Genetic Citizenship'. *A Companion to the Anthropology of Politics*, 152.
- Herzfeld, Michael. 1993. *The Social Production of Indifference: Exploring the Symbolic Roots of Western Bureaucracy*. Chicago: University of Chicago Press.
- Ho, T. M., and L. Cordovilla. 2004. 'Our Dilemma: The Self-Marginal People'. *EDTNA/ERCA Journal (English Ed.)* 30 (4): 230–33.
- Holmes, Seth M. 2013. *Fresh Fruit, Broken Bodies: Migrant Farmworkers in the United States*. California Series in Public Anthropology ; 27. Berkeley: University of California Press. <http://UCL.ebib.com/patron/FullRecord.aspx?p=1184054>.
- HUMA Network. 2009. 'Access to Health Care for Undocumented Migrants and Asylum Seekers in 10 EU Countries'. [http://www.episouth.org/doc/r\\_documents/Rapport\\_huma-network.pdf](http://www.episouth.org/doc/r_documents/Rapport_huma-network.pdf).

- Huschke, Susanne. 2014. 'Performing Deservingness. Humanitarian Health Care Provision for Migrants in Germany'. *Social Science & Medicine* 120 (November): 352–59. doi:10.1016/j.socscimed.2014.04.046.
- Inhorn, Marcia C. 2004. 'Privacy, Privatization, and the Politics of Patronage: Ethnographic Challenges to Penetrating the Secret World of Middle Eastern, Hospital-Based in Vitro Fertilization'. *Social Science & Medicine, Hospital Ethnography*, 59 (10): 2095–2108. doi:10.1016/j.socscimed.2004.03.012.
- Institute of Medicine. 2003. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care - PubMed - NCBI*. Edited by BD Smedley, AY Stith, and AR Nelson. Washington, D.C: National Academies Press (US). <https://www.ncbi.nlm.nih.gov/pubmed/25032386>.
- Ioakimidis, Vasilios, Clara Cruz Santos, and Ines Martinez Herrero. 2014. 'Reconceptualizing Social Work in Times of Crisis: An Examination of the Cases of Greece, Spain and Portugal'. *International Social Work* 57 (4): 285–300.
- Jenks, Angela C. 2011. 'From "Lists of Traits" to "Open-Mindedness": Emerging Issues in Cultural Competence Education'. *Culture, Medicine, and Psychiatry* 35 (2): 209–35. doi:10.1007/s11013-011-9212-4.
- Joseph, G. M, and Daniel Nugent, eds. 1994. *Everyday Forms of State Formation: Revolution and the Negotiation of Rule in Modern Mexico*. Durham N.C. ; London: Duke University Press.
- Kehr, Janina. 2012. 'Blind Spots and Adverse Conditions of Care: Screening Migrants for Tuberculosis in France and Germany'. *Sociology of Health & Illness* 34 (2): 251–65. doi:10.1111/j.1467-9566.2011.01415.x.
- . 2014. 'Against Sick States: Ebola Protests in Austerity Spain'. *Somatosphere*. <http://somatosphere.net/2014/10/against-sick-states.html>.
- . 2016. 'The Precariousness of Public Health: On Tuberculosis Control in Contemporary France'. *Medical Anthropology* 35 (5): 377–89. doi:10.1080/01459740.2015.1091819.
- Kirmayer, Laurence J. 2012. 'Rethinking Cultural Competence'. *Transcultural Psychiatry* 49 (2): 149–64. doi:10.1177/1363461512444673.
- Kleinman, Arthur. 1978. 'Concepts and a Model for the Comparison of Medical Systems as Cultural Systems'. *Social Science & Medicine. Part B: Medical Anthropology* 12: 85–93.
- La Parra, Daniel, Diana Gil-González, and Antonio Jiménez. 2013. 'Los procesos de exclusión social y la salud del pueblo gitano en España'. *Gaceta Sanitaria* 27 (5): 385–86. doi:10.1016/j.gaceta.2013.05.001.
- Lambek, H., and L. Sevak. 1996. 'Is "Cultural Difference" a Useful Concept? Perceptions of Health and the Sources of Ill Health among Londoners of South Asian Origin.' In *Researching Cultural Differences in Health*, edited by David Kelleher and S. M Hillier, 124–59. London: Routledge.
- Lambek, Michael, ed. 2010. *Ordinary Ethics: Anthropology, Language, and Action*. New York: Fordham University Press.
- Lamont, M., S. Beljean, and M. Clair. 2014. 'What Is Missing? Cultural Processes and Causal Pathways to Inequality'. *Socio-Economic Review* 12 (3): 573–608. doi:10.1093/ser/mwu011.

- Lamont, Michèle, and Virág Molnár. 2002. 'The Study of Boundaries in the Social Sciences'. *Annual Review of Sociology* 28 (1): 167–95.  
doi:10.1146/annurev.soc.28.110601.141107.
- Lamont, Michele, and Mario Luis Small. 2006. 'How Culture Matters for Poverty: Thickening Our Understanding'. In *The Colors of Poverty (Forthcoming)*, edited by David Harris and Ann Lin. New York: Russell Sage Foundation.  
[http://npc.umich.edu/publications/workingpaper06/paper10/working\\_paper06-10.pdf](http://npc.umich.edu/publications/workingpaper06/paper10/working_paper06-10.pdf).
- Larchanché, Stéphanie. 2012. 'Intangible Obstacles: Health Implications of Stigmatization, Structural Violence, and Fear among Undocumented Immigrants in France'. *Social Science & Medicine* 74 (6): 858–63.  
doi:10.1016/j.socscimed.2011.08.016.
- Legido-Quigley, H., L. Otero, D. I. Parra, C. Alvarez-Dardet, J. M. Martin-Moreno, and M. McKee. 2013. 'Will Austerity Cuts Dismantle the Spanish Healthcare System?' *BMJ* 346 (jun13 1): f2363–f2363. doi:10.1136/bmj.f2363.
- Liégeois, Jean-Pierre. 1995. *Roma/Gypsies: A European Minority*. Report (Minority Rights Group); 95/4. London: Minority Rights Group.
- Lindenbaum, Shirley, and Margaret M Lock. 1993. *Knowledge, Power, and Practice: The Anthropology of Medicine and Everyday Life*. Comparative Studies of Health Systems and Medical Care, no. 36. Berkeley: University of California Press.
- Lipsky, Michael. 1980. *Street Level Bureaucracy: Dilemmas of the Individual in Public Services*. New York: Russell Sage Foundation.
- Littlewood, Roland, and Maurice Lipsedge. 1997. *Aliens and Alienists: Ethnic Minorities and Psychiatry*. 3rd ed. London; New York: Routledge.
- Lochlan Jain, S., and Sharon R. Kaufman. 2011. 'Introduction to Special Issue After Progress: Time and Improbable Futures in Clinic Spaces'. *Medical Anthropology Quarterly* 25 (2): 183–88. doi:10.1111/j.1548-1387.2011.01148.x.
- López Catalán, Oscar. 2012. 'The Genesis of a "Romanian Roma Issue" in the Metropolitan Area of Barcelona: Urban Public Spaces, Neighbourhood Conflicts and Local Politics'. *Revista de Estudios Urbanos y Ciencias Sociales*. 2 (1): 95–117.
- López Catalán, Oscar, and Noura Aharchi. 2012. 'Discursos Sobre La Inmigración Rrom (Gitana) Rumana En Barcelona. Estudio de La Representación Del Conflicto Vecinal y Los Trabajos Marginales a Partir de El País, La Vanguardia y El Periódico de Catalunya (2006-2011)'. *Discurso & Sociedad* 6 (3): 543–590.
- Lovell, Anne M. 1992. 'Seizing the Moment: Power, Contingency, and Temporality in Street Life'. In *The Politics of Time*, edited by Henry J. Rutz. American Ethnological Society Monograph Series, no. 4. Washington, D.C: American Anthropological Association.
- . 1997. "'The City Is My Mother": Narratives of Schizophrenia and Homelessness'. *American Anthropologist* 99 (2): 355–368.
- Löwy, Ilana. 1995. "'Nothing More to Be Done": Palliative Care Versus Exerimental Therapy in Advanced Cancer'. *Science in Context* 8 (01): 209–29.  
doi:10.1017/S0269889700001964.

- Luna Sánchez, Antonio, Luis Miguel Rodríguez Benjumedá, and Paula Cristina Ortega Sánchez. 2013. 'Análisis de Un Brote de Sarampión En Una Barriada de La Provincia de Sevilla, España'. *Revista Española de Salud Pública* 87 (3): 257–66. doi:10.4321/S1135-57272013000300005.
- Lupton, Deborah. 1994. *Medicine as Culture: Illness, Disease and the Body in Western Societies*. London: Sage.
- . 1999. *Risk*. Key Ideas. Y. London: Routledge.
- Magazzini, Tina, and Stefano Piemontese. 2016. "'Roma" Migration in the EU: The Case of Spain between "New" and "Old" Minorities'. *Migration Letters; Luton* 13 (2): 228–41.
- Malmusi, Davide, Laia Palència, Umar Ikram, Anton Kunst, and Carme Borrell. 2015. 'Social and Political Determinants of Inequalities in Depression by Immigrant Status in Europe Davide Malmusi'. *European Journal of Public Health* 25 (suppl\_3). doi:10.1093/eurpub/ckv167.056.
- Martin, Elisa, and Juan F. Gamella. 2005. 'Marriage Practices and Ethnic Differentiation: The Case of Spanish Gypsies (1870–2000)'. *The History of the Family* 10 (1): 45–63. doi:10.1016/j.hisfam.2004.03.004.
- Martin-Moreno, Jose M., Paloma Alonso, Ana Claveria, Lydia Gorgojo, and Salvador Peiró. 2009. 'Spain: A Decentralised Health System in Constant Flux'. *BMJ* 338 (March): b1170. doi:10.1136/bmj.b1170.
- Marushiakova, Elena, and Veselin Popov. 2011. 'Between Exoticization and Marginalization. Current Problems of Gypsy Studies'. *Behemoth* 4 (1). doi:10.1515/behemoth.2011.006.
- May, Carl. 1992. 'Individual Care? Power and Subjectivity in Therapeutic Relationships'. *Sociology* 26 (4): 589–602.
- Maya Ovalle, Ostalina, and Anna Mirga. 2014. 'The Myth of the Spanish Model of Roma Inclusion'. <http://www.romea.cz/en/news/world/ostalinda-maya-ovalle-the-myth-of-the-spanish-model-of-roma-inclusion>.
- Meissner, Fran, and Steven Vertovec. 2015. 'Comparing Super-Diversity'. *Ethnic and Racial Studies* 38 (4): 541–55. doi:10.1080/01419870.2015.980295.
- Mercan, Aline. 2009. 'Quand identités de médecin et d'anthropologue s'enmêlent : conséquences sur affectations, affects et éthique'. *ethnographiques.org*, no. Numéro 17-novembre 2008. <http://www.ethnographiques.org/2008/Mercan>.
- Mitsuf Gallardo, M. J., J. Martínez de la Iglesia, M. Muñoz Álamo, M. J. Fernández Fernández, N. Lora Cerezo, and R. M. Dueñas Herrero. 1997. 'Influencia de factores socioeconómicos en la evolución y seguimiento del embarazo'. *Atención Primaria* 19 (4): 188–94.
- Mol, Annemarie. 2002. *The Body Multiple: Ontology in Medical Practice*. London: Durham, N.C.; Duke University Press.
- . 2008. *The Logic of Care: Health and the Problem of Patient Choice*. 1st ed. London; New York: Routledge.

- Mol, Annemarie, Ingunn Moser, and Jeannette Pols, eds. 2010. *Care in Practice: On Tinkering in Clinics, Homes and Farms*. 1. Aufl. VerKörperungen 8. Bielefeld: Transcript-Verl.
- Mosse, David. 2006. 'Anti-Social Anthropology? Objectivity, Objection, and the Ethnography of Public Policy and Professional Communities\*'. *Journal of the Royal Anthropological Institute* 12 (4): 935–56.
- MSC, and FSG. 2005. 'Health and the Roma Community, Analysis of Action Proposals'. Madrid: Ministerio de Salud y Consumo.
- MSPS. 2006. 'Hacia La Equidad En Salud, Disminuir Las Desigualdades En Una Generación En La Comunidad Gitana, Estudio Comparativo de Las Encuestas Nacionales de Salud a Población Gitana y Población General de España, 2006'. Madrid: Ministerio de Salud y Política Social.
- MSPSI. 2011. 'Diagnóstico social de la comunidad gitana en España, Un análisis contrastado de la Encuesta del CIS a Hogares de Población Gitana 2007'. Madrid: Ministerio de Salud, Políticas Social e Igualdad.
- MSSSI. 2012. 'National Roma Integration Strategy in Spain 2012-2020'. Madrid: Ministerio de Salud, Servicios Sociales e Igualdad.
- . 2016. 'Segunda Encuesta Nacional de Salud a Población Gitana 2014'. Madrid: Ministerio de Salud, Servicios Sociales e Igualdad.  
[https://www.gitanos.org/upload/58/44/Segunda\\_Encuesta\\_Nacional\\_de\\_Salud\\_a\\_Poblacion\\_Gitana\\_2014.pdf](https://www.gitanos.org/upload/58/44/Segunda_Encuesta_Nacional_de_Salud_a_Poblacion_Gitana_2014.pdf).
- Murphy, Michelle. 2012. *Seizing the Means of Reproduction Entanglements of Feminism, Health, and Technoscience*. Experimental Futures Y. Durham, N.C.: Duke University Press. <http://dx.doi.org/10.1215/9780822395805>.
- Napier, A. David, Clyde Ancarno, Beverley Butler, Joseph Calabrese, Angel Chater, Helen Chatterjee, François Guesnet, et al. 2014. 'Culture and Health'. *The Lancet* 384 (9954): 1607–39. doi:10.1016/S0140-6736(14)61603-2.
- Navarro, Vicente. 1986. *Crisis, Health, and Medicine: A Social Critique*. New York; London: Tavistock.
- Nguyen, Vinh-Kim. 2010. *The Republic of Therapy: Triage and Sovereignty in West Africa's Time of AIDS*. Body, Commodity, Text Y. Durham, NC; London: Duke University Press.
- Nguyen, Vinh-Kim, and Karine Peschard. 2003. 'Anthropology Inequality and Disease: A Review'. *Annual Review of Anthropology* 32 (1): 447–74. doi:10.1146/annurev.anthro.32.061002.093412.
- Nogués Sáez, Luis. 2010. *Exclusión Residencial y Políticas Públicas [Recurso Electrónico]: El Caso de La Minoría Gitana En Madrid (1986-2006)*. (Tesis Doctoral). Granada]: Editorial de la Universidad de Granada.
- Olivier de Sardan, Jean-Pierre. 2010. 'Anthropologie médicale et socio-anthropologie des actions publiques: Dispositifs de recherche, commanditaires, réformes...'. *Anthropologie et Santé*, no. 1 (October). doi:10.4000/anthropologiesante.86.
- Ong, Aihwa. 1995. 'Making the Biopolitical Subject: Cambodian Immigrants, Refugee Medicine and Cultural Citizenship in California'. *Social Science & Medicine* 40 (9): 1243–57. doi:10.1016/0277-9536(94)00230-Q.

- . 2005. '(Re)Articulations of Citizenship'. *PS: Political Science & Politics* 38 (04): 697–99. doi:10.1017/S1049096505050377.
- . 2006. 'Mutations in Citizenship'. *Theory, Culture & Society* 23 (2–3): 499–505. doi:10.1177/0263276406064831.
- Ootes, S.T.C. 2012. 'Being in Place: Citizenship in Long-Term Mental Healthcare'. UvA-DARE. [https://pure.uva.nl/ws/files/2290387/114834\\_thesis.pdf](https://pure.uva.nl/ws/files/2290387/114834_thesis.pdf).
- Ootes, S.T.C., A.J. Pols, E.H. Tonkens, and D.L. Willems. 2013. 'Where Is the Citizen? Comparing Civic Spaces in Long-Term Mental Healthcare'. *Health & Place* 22 (July): 11–18. doi:10.1016/j.healthplace.2013.02.008.
- Ortega, Eduardo, and David García. 2015. 'El Gasto Sanitario Respecto Al PIB Caerá Al 5,6%'. *Redacción Médica*. <http://www.redaccionmedica.com/noticia/el-gasto-sanitario-respecto-al-pib-cae-al-56-87948>.
- Ortiz Gómez, Teresa. 2005. 'Fuentes orales e identidades profesionales: Médicas españolas en la segunda mitad del siglo XX'. *Asclepio* 57 (1): 75–98.
- Pablo, Rosario de, Carlos Vilches, Maria E. Moreno, M. Carmen Rementería, Rosario Solís, and Miguel Kreisler. 1992. 'Distribution of HLA Antigens in Spanish Gypsies: A Comparative Study'. *Tissue Antigens* 40 (4): 187–96. doi:10.1111/j.1399-0039.1992.tb02044.x.
- Padilla, Javier. 2016. 'Seis Dudas y Siete Gráficas Sobre Gasto Sanitario En España'. *Periodico Diagonal*. <https://www.diagonalperiodico.net/blogs/javierpadillab/6-dudas-y-7-graficas-sobre-gasto-sanitario-espana.html>.
- Pajares, Miguel. 2007. *Inmigrantes Del Este: Procesos Migratorios de Los Rumanos*. Icaria Antrazyt 252. Barcelona: Icaria Editorial.
- Peinado-Gorlat, Patricia, Francisco Javier Castro-Martínez, Beatriz Arriba-Marcos, Miguel Melguizo-Jiménez, and Inés Barrio-Cantalejo. 2015. 'Roma Women's Perspectives on End-of-Life Decisions'. *Journal of Bioethical Inquiry* 12 (4): 687–98. doi:10.1007/s11673-015-9656-2.
- Pérez Jarauta, Maria José, Maria ángeles Goya Arive, and Begoña Merino Merino. 2010. 'Spain: Health Promotion among Navarre Ethnic Minorities Programme'. In *Poverty and Social Exclusion in the WHO European Region: Health Systems Respond*, edited by Theadora Koller and Weltgesundheitsorganisation, 178–95. Copenhagen: WHO, Regional Office for Europe.
- Petryna, Adriana. 2002. *Life Exposed: Biological Citizens after Chernobyl*. In-Formation Series Y. Princeton, N.J.; Oxford: Princeton University Press.
- Phillimore, Jenny. 2015. 'Delivering Maternity Services in an Era of Superdiversity: The Challenges of Novelty and Newness'. *Ethnic and Racial Studies* 38 (4): 568–82. doi:10.1080/01419870.2015.980288.
- Picker, Giovanni. 2012. 'Left-Wing Progress? Neo-Nationalisms and the Case of Romany Migrants in Italy'. In *The Gypsy 'Menace': Populism and the New Anti-Gypsy Politics*, edited by Michael Stewart. London: Hurst.
- . 2016. "'That Neighbourhood Is an Ethnic Bomb!'" The Emergence of an Urban Governance Apparatus in Western Europe'. *European Urban and Regional Studies* 23 (2): 136–48. doi:10.1177/0969776413502659.

- Picker, Giovanni, and Gabriele Roccheggiani. 2014. 'Abnormalising Minorities. The State and Expert Knowledge Addressing the Roma in Italy'. *Identities* 21 (2): 185–201. doi:10.1080/1070289X.2013.854719.
- Pols, Jeannette. 2006. 'Washing the Citizen: Washing, Cleanliness and Citizenship in Mental Health Care'. *Culture, Medicine and Psychiatry* 30 (1): 77–104. doi:10.1007/s11013-006-9009-z.
- . 2016. 'Analyzing Social Spaces: Relational Citizenship for Patients Leaving Mental Health Care Institutions'. *Medical Anthropology* 35 (2): 177–92. doi:10.1080/01459740.2015.1101101.
- Pols, Jeannette, and Ingunn Moser. 2009. 'Cold Technologies versus Warm Care? On Affective and Social Relations with and through Care Technologies'. *ALTER - European Journal of Disability Research / Revue Européenne de Recherche Sur Le Handicap* 3 (2): 159–78. doi:10.1016/j.alter.2009.01.003.
- Porter, Theodore M. 1988. *The Rise of Statistical Thinking: 1820 - 1900*. Nachdr. Princeton Paperbacks. Princeton, NJ: Princeton Univ. Press.
- Povinelli, Elizabeth A. 2011. *Economies of Abandonment Social Belonging and Endurance in Late Liberalism*. Durham [N.C.], Durham, [N.C.]; London: Duke University Press. <http://dx.doi.org/10.1215/9780822394570>.
- Preciado, Paul B. 2013. *Testo Junkie: Sex, Drugs, and Biopolitics in the Pharmacopornographic Era*. Translated by Bruce Benderson. New York, NY: The Feminist Press at the City University of New York.
- Quesada, James, Laurie Kain Hart, and Philippe Bourgois. 2011. 'Structural Vulnerability and Health: Latino Migrant Laborers in the United States'. *Medical Anthropology* 30 (4): 339–62. doi:10.1080/01459740.2011.576725.
- Rabinow, Paul. 1996. *Essays on the Anthropology of Reason*. Princeton Studies in Culture/Power/History. Y. Princeton, N.J: Princeton University Press.
- Ramos-Morcillo, Antonio Jesús, María Ruzafa-Martínez, Serafin Fernández-Salazar, and Rafael del-Pino-Casado. 2014. 'Expectativas y experiencias de uso de las mujeres gitanas mayores ante los servicios sanitarios de atención primaria'. *Atención Primaria*, August. doi:10.1016/j.aprim.2014.05.011.
- Rapp, Rayna. 1999. *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America*. New York: Routledge Ltd.
- Real Llorente, M. del, J. Pellegrini Belinchon, and A. del Molino Anta. 2000. 'Mantenimiento de la lactancia materna'. *Anales de Pediatría* 52 (1): 69. doi:10.1016/S1695-4033(00)77297-3.
- Redfield, Peter. 2005. 'Doctors, Borders, and Life in Crisis'. *Cultural Anthropology* 20 (3): 328–61. doi:10.1525/can.2005.20.3.328.
- Reyniers, Alain. 1995. 'Gypsy Populations and Their Movements within Central and Eastern Europe and towards Some OECD Countries'. <https://halshs.archives-ouvertes.fr/halshs-00089389/>.
- Río Ruiz, Manuel Ángel. 2009. *Dinámicas de Exclusión Social En El Marco de Políticas de Inclusión Étnica: Comunidad Gitana, Operaciones de Realojamiento y Relaciones Étnicas En España*. Sevilla: Centro de Estudios Andaluces.



- Riska, Elianne. 2001. 'Towards Gender Balance: But Will Women Physicians Have an Impact on Medicine?' *Social Science & Medicine*, The Physicians Role in Transition, 52 (2): 179–87. doi:10.1016/S0277-9536(00)00218-5.
- Rodríguez García, Dan, and Teresa San Román Espinosa. 2007. 'Inmigración, Salud y Gestión de La Diversidad: Presentación y Avances de Un Proyecto En Barrios de Cataluña'. *AIBR: Revista de Antropología Iberoamericana* 2 (3): 489–520.
- Román, Teresa San. 1997. *La diferencia inquietante: viejas y nuevas estrategias culturales de los gitanos*. <https://dialnet.unirioja.es/servlet/libro?codigo=245927>.
- Rose, Nikolas. 2001. 'The Politics of Life Itself'. *Theory, Culture & Society* 18 (6): 1–30. doi:10.1177/02632760122052020.
- Rose, Nikolas, and Carlos Novas. 2008. 'Biological Citizenship'. In *Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems*, edited by Aihwa Ong and Stephen J. Collier, 439–63. Oxford, UK: Blackwell Publishing Ltd. <http://doi.wiley.com/10.1002/9780470696569.ch23>.
- Rylko-Bauer, Barbara, and Paul Farmer. 2002. 'Managed Care or Managed Inequality? A Call for Critiques of Market-Based Medicine'. *Medical Anthropology Quarterly* 16 (4): 476–502. doi:10.1525/maq.2002.16.4.476.
- Sàez Sellarès, Meritxell, and Oscar López Catalán. 2009. 'La població rrom immigrant de romania a Catalunya: Accés i ús dels serveis sanitaris catalans i situació de salut'. Barcelona: UAB.
- Saletti Cuesta, Lorena. 2015. *Discurso de Las Médicas Sobre El Desarrollo Profesional: Miradas Propias*. Feminae 28. Granada: Universidad de Granada.
- Salud Madrid. 2005. 'Situación de Los Asentamientos Marginales Del Área Sanitaria 1'. Madrid.
- San Román, Teresa. 2010. *La diferencia inquietante: viejas y nuevas estrategias culturales de los gitanos*. Madrid: Siglo XXI de España Editores.
- Santiago-Irizarry, Vilma. 1996. 'Culture as Cure'. *Cultural Anthropology* 11 (1): 3–24.
- Sargent, Carolyn. 2012. 'Special Issue Part I: "Deservingness" and the Politics of Health Care'. *Social Science & Medicine* 74 (6): 855–57. doi:10.1016/j.socscimed.2011.10.044.
- Sargent, Carolyn, and Stéphanie Larchanché. 2011. 'Transnational Migration and Global Health: The Production and Management of Risk, Illness, and Access to Care'. *Annual Review of Anthropology* 40 (1): 345–61. doi:10.1146/annurev-anthro-081309-145811.
- Sarradon-Eck, Aline. 2009. 'Médecin et anthropologue, médecin contre anthropologue : dilemmes éthiques pour ethnographes en situation clinique'. *ethnographiques.org*, no. Numéro 17-novembre 2008. <http://www.ethnographiques.org/2008/Sarradon-Eck>.
- Sarradon-Eck, Aline, Cyril Farnarier, and Takeo David Hymans. 2014. 'Caring on the Margins of the Healthcare System'. *Anthropology & Medicine* 21 (2): 251–63. doi:10.1080/13648470.2014.924299.
- Schneider, Jane, and Peter T. Schneider. 1996. *Festival of the Poor: Fertility Decline & the Ideology of Class in Sicily, 1860–1980*. Hegemony and Experience. Y. Tucson: University of Arizona Press.

- Seoane, Luis, and Paloma Portero. 2006. 'Actitudes y demandas de los profesionales de la salud hacia la atención sanitaria de los inmigrantes'. Servicio de Promoción de la Salud.
- Shaw, Susan J. 2005. 'The Politics of Recognition in Culturally Appropriate Care'. *Medical Anthropology Quarterly* 19 (3): 290–309.
- Sigona, Nando, and Peter Vermeersch. 2012. 'Editors' Introduction. The Roma in the New EU: Policies, Frames and Everyday Experiences'. *Journal of Ethnic and Migration Studies* 38 (8): 1189–93. doi:10.1080/1369183X.2012.689174.
- Simó, Juan. 2015. 'No Todo Es Clínica, Aseguramiento Sanitario Público En España, Situación Actual y Tareas Pendientes'. *Actualización En Medicina de Familia* 11 (9) (October): 504–11.
- . 2017. 'El "Descremado" Sociológico de La Atención Primaria Española'. *El Médico Interactivo*. Accessed March 4.  
<http://www.elmedicointeractivo.com/articulo/tribuna/descremado-sociologico-atencion-primaria-espanola/20170208151650110293.html>.
- Simó, Juan, and Juan Gervas. 2012. 'Gasto Sanitario En Atención Primaria En España: Insuficiente Para Ofrecer Servicios Atrayentes Para Pacientes y Profesionales. Informe SESPAS 2012'. *Gaceta Sanitaria* 26, Supplement 1 (March): 36–40. doi:10.1016/j.gaceta.2011.05.017.
- Soler-González, Jorge, Catalina Serna Arnáiz, Montserrat Rué Monné, Anna Bosch Gaya, María Cristina Ruiz Magaz, and Javier Gervilla Caño. 2008. 'Utilización de recursos de atención primaria por parte de inmigrantes y autóctonos que han contactado con los servicios asistenciales de la ciudad de Lleida'. *Atención Primaria* 40 (5): 225–31. doi:10.1157/13120019.
- Starfield, Barbara. 1998. *Primary Care: Balancing Health Needs, Services, and Technology*. Oxford University Press.
- Stevenson, Lisa. 2012. 'The Psychic Life of Biopolitics: Survival, Cooperation, and Inuit Community'. *American Ethnologist* 39 (3): 592–613. doi:10.1111/j.1548-1425.2012.01383.x.
- Stewart, Michael, ed. 2012. *The Gypsy 'Menace': Populism and the New Anti-Gypsy Politics*. London: Hurst.
- Stolcke, Verena. 1995. 'Talking Culture: New Boundaries, New Rhetorics of Exclusion in Europe'. *Current Anthropology* 36 (1): 1–24.
- Strathern, Marilyn. 1996. 'Cutting the Network'. *The Journal of the Royal Anthropological Institute* 2 (3): 517–35. doi:10.2307/3034901.
- Suárez Navaz, Liliana. 1999. 'La Construcción Social Del "Fetichismo de Los Papeles": Ley e Identidad En La Frontera Sur de Europa'. *VIII Congreso Antropología 4: Antropología Jurídica: Dimposio IV*: 89–102.
- Surdu, Mihai, and Martin Kovats. 2015. 'Roma Identity as an Expert-Political Construction'. *Social Inclusion* 3 (5): 5. doi:10.17645/si.v3i5.245.
- Swinglehurst, Deborah, Trisha Greenhalgh, and Celia Roberts. 2012. 'Computer Templates in Chronic Disease Management: Ethnographic Case Study in General Practice'. *BMJ Open* 2 (6): 1–15.

- Taylor, Janelle S. 2003. 'The Story Catches You and You Fall Down: Tragedy, Ethnography, and "Cultural Competence'.' *Medical Anthropology Quarterly* 17 (2): 159–181.
- Ticktin, Miriam. 2006. 'Where Ethics and Politics Meet'. *American Ethnologist* 33 (1): 33–49. doi:10.1525/ae.2006.33.1.33.
- . 2011a. *Casualties of Care: Immigration and the Politics of Humanitarianism in France*. UPCC Book Collections on Project MUSE. Berkeley: University of California Press.
- . 2011b. 'How Biology Travels: A Humanitarian Trip'. *Body & Society* 17 (2–3): 139–58. doi:10.1177/1357034X11400764.
- Timmermans, Stefan, and Marc Berg. 2003. *The Gold Standard: The Challenge Of Evidence-Based Medicine*. Temple University Press.
- Trehan, Nidhi, and Nando Sigona, eds. 2009. *Romani Politics in Contemporary Europe: Poverty, Ethnic Mobilization, and the Neoliberal Order*. Basingstoke: Palgrave Macmillan.
- Tronto, Joan C. 1994. *Moral Boundaries: A Political Argument for an Ethic of Care*. New York: Routledge.
- Van Baar, Huub. 2014. 'The Emergence of a Reasonable Anti-Gypsyism in Europe'. In *When Stereotype Meets Prejudice: Antiziganism in European Societies*, edited by Timofey Agarin, 25–42. Stuttgart: ibidem-Verlag.
- Van Cleemput, Patrice, Glenys Parry, Kate Thomas, Jean Peters, and Cindy Cooper. 2007. 'Health-Related Beliefs and Experiences of Gypsies and Travellers: A Qualitative Study'. *Journal of Epidemiology and Community Health* 61 (3): 205–10. doi:10.1136/jech.2006.046078.
- Vázquez, María-Luisa, Rebeca Terraza-Núñez, Ingrid Vargas, Dolors Rodríguez, and Tona Lizana. 2011. 'Health Policies for Migrant Populations in Three European Countries: England; Italy and Spain'. *Health Policy* 101 (1): 70–78. doi:10.1016/j.healthpol.2010.08.026.
- Vermeersch, Peter. 2012. 'Reframing the Roma: EU Initiatives and the Politics of Reinterpretation'. *Journal of Ethnic and Migration Studies* 38 (8): 1195–1212. doi:10.1080/1369183X.2012.689175.
- Vertovec, Steven. 2007. 'Super-Diversity and Its Implications'. *Ethnic and Racial Studies* 30 (6): 1024–54. doi:10.1080/01419870701599465.
- . , ed. 2014. *Routledge International Handbook of Diversity Studies*. Routledge Handbooks Online. <https://www-routledgehandbooks-com.libproxy.ucl.ac.uk/doi/10.4324/9781315747224>.
- Vertovec, Steven, and Susanne Wessendorf, eds. 2010. *The Multiculturalism Backlash: European Discourses, Policies and Practices*. London: Routledge.
- Viruela Martínez, Rafael. 2008. 'Población Rumana y Búlgara En España: Evolución, Distribución Geográfica y Flujos Migratorios'. *Cuadernos de Geografía*, no. 84: 169–194.
- Wacquant, Loïc JD. 1997. 'Three Pernicious Premises in the Study of the American Ghetto'. *International Journal of Urban and Regional Research* 21 (2): 341–353.

- White, Paul, Alexandra Hillman, and Joanna Latimer. 2012. 'Ordering, Enrolling, and Dismissing: Moments of Access Across Hospital Spaces'. *Space and Culture* 15 (1): 68–87. doi:10.1177/1206331211426063.
- Willen, Sarah S. 2012a. 'Migration, "Illegality," and Health: Mapping Embodied Vulnerability and Debating Health-Related Deservingness'. *Social Science & Medicine (1982)* 74 (6): 805–11. doi:10.1016/j.socscimed.2011.10.041.
- . 2012b. 'How Is Health-Related "Deservingness" Reckoned? Perspectives from Unauthorized Im/Migrants in Tel Aviv'. *Social Science & Medicine* 74 (6): 812–21. doi:10.1016/j.socscimed.2011.06.033.